

Subjective psychosocial experiences of South African breast cancer patients receiving diagnosis and treatment

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PLAGIARISM DECLARATION

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ABSTRACT

The present study is an attempt to explore, describe, and interpretively understand the lived psychosocial experiences of individual breast cancer patients receiving diagnosis and treatment from a first-person perspective. The aim of this study was to provide subjective evidence of high significance, emphasizing the importance of incorporating customized psychosocial support as part of multidisciplinary health care. Customized psychosocial support could potentially increase positive health outcomes. This qualitative study adopted a case study design using a phenomenological research approach. Interpretative Phenomenological Analysis (IPA) was the explorative and flexible research method of choice. The participants were purposively selected. Participant selection was based on shared characteristics. Data were collected from 10 eligible breast cancer patients reporting at the Breast Clinic, from which three case studies were selected for analysis. Semi-structured interviews were employed for data collection. Narratives were audio recorded and transcribed by the researcher. The analysis of each of the selected three case studies led to the emergence of a single overarching psychological concept of what it means to live with breast cancer, namely, loss of personal identity. The findings across the three case studies revealed similarities within different experiences, as well as differences within similar experiences. Perceptions of breast cancer were shaped by parental influences, perceived lack of knowledge and obscurity. Experiences pertaining to breast cancer diagnosis included repudiation, experiential avoidance, fatalism and transient global amnesia. Experiences related to treatment interventions contained the following descriptions: trauma, mortification, indignity, maiming, humiliation, and demoralization. Meaning-making included incremental living, mindfulness, self-transcendence, as well as surrender. Two main theoretical frameworks namely, the Biopsychosocial Spiritual Model and Constructivism were identified for contextualization of interpreted findings. Participants' descriptions demonstrated the significant impact of breast cancer on psychological, emotional, social and physical domains of women's lives. The loss of a

woman's breasts comprises more than just a physical loss. The loss of a woman's breast encompasses a loss of personal identity. Living with breast cancer and related experiences are unexplored areas in South African Women's Health Psychology. This study illustrates the value of exploring particular existential breast cancer experiences in developing customized health care. This study provides a foundation for future (larger and more representative) studies that can build on the findings of this study.

Keywords: Breast cancer, personal existential experiences, diagnosis, and treatment, personal identity, Interpretative Phenomenological Analysis

OPSOMMING

Die huidige studie het ten doel om die geleefde ervaringe van individuele borskanker pasiënte, ten opsigte van diagnose en behandeling, te ondersoek, beskryf en met begrip te interpreteer vanuit 'n eerste-persoon perspektief. Die doel van die studie was om subjektiewe bewyse van hoë betekenis te lewer, met 'n klem op die belangrikheid van insluiting van persoonlike psigososiale ondersteuning as deel van multidisiplinêre gesondheidsorg. Persoonlike psigososiale ondersteuning kan moontlik 'n verhoging in positiewe gesondheidsuitkomst tot gevolg hê. Hierdie kwalitatiewe studie het 'n gevallestudie ontwerp en maak gebruik van 'n fenomenologiese navorsingsbenadering. Interpretatiewe Fenomenologiese Analise was die ondersoekende en buigsame navorsingsmetode van keuse. Die deelnemers was doelgerig gekies. Deelnemer seleksie was gebasseer op gemene eienskappe. Inligting is verkry van 10 verdienstelike deelnemers wat aanmeld by die Borskliniek, waaruit drie gevalle studies geselekteer is vir ontleding. Semi-gestruktureerde onderhoude is gebruik om inligting te versamel. Vertellings is aangeteken as klankopnames en deur die navorser getranskribeer. Die analisering van die gekose gevallestudies het aanleiding gegee tot die ontluiking van 'n enkel, oorkoeplende psigologiese konsep rakende die betekenis van 'n lewe met borskanker, naamlik die verlies van persoonlike identiteit. Die bevindinge van die drie gevallestudies het getoon daar is verskille in ooreenstemmende ervaringe asook ooreenkomste in verskillende ervaringe. Persepsies van borskanker is onder andere beïnvloed deur ouerlike invloede, verwagte verlies aan kennis en onbekendheid. Ervaring wat verband hou met borskanker diagnose sluit in verwerping, vermyding van die ervaring, fatalisme en verbygaande globale amnesie. Ervaringe wat verband hou met behandeling omvat die volgende beskrywings naamlik, trauma, tugtiging, vernedering, verminking en demoralisering. Betekenis maak sluit in inkrementele lewe, bewustheid, self-transendensie en oorgawe. Twee hoof teoretiese raamwerke naamlik die Biopsigososiale Spirituele model en Konstruktivisme is geïdentifiseer vir kontekstualisering van geïnterpreteerde

bevindinge. Deelnemers se beskrywinge het gedemonstreer dat borskanker 'n betekenisvolle impak het op psigologiese, emosionele, sosiale en fisiese vlakke van 'n vrou se lewe. Die verlies van 'n vrou se bors (borste) is meer as net 'n fisiese verlies. Die verlies van 'n vrou se bors omvat die verlies van persoonlike identiteit. Om te leef met borskanker, en verwante ervarings, is onverkende areas in Suid Afrikaanse Vroue Gesondheidpsigologie. Hierdie studie illustreer die waarde van die verkenning van spesifieke eksistensiële borskanker ervarings om persoonlike gesondheidsorg te ontwikkel. Die bevindinge van hierdie studie kan dien as 'n basis vir toekomstige (groter en meer verteenwoordigende) studies .

Sleutelwoorde: Borskanker, persoonlike eksistensiële ervarings, diagnose en behandeling, persoonlike identiteit, Interpretatiewe Fenomenologiese Analise

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Herewith my acknowledgments and heartfelt gratitude:

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“Perfection is the willingness to be imperfect” – Lao Tsu

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“The best teachers are those who show you where to look but don’t tell you what to see” –

Unknown

My co-supervisor Dr. Roomaney, I want to express my gratitude for your guidance.

“I am not a product of my circumstances. I am a product of my decisions.” – Steven Covey

Sr. September and colleagues at the Breast Clinic, you are the reason women believe in goodness; your kindness is changing lives, growing spirits and strengthening souls.

“To do what nobody else will do, a way that nobody else can do, in spite of all we go through; that is to be a nurse.” – Rawsie Williams

My husband Ian, I look into your eyes, and I find myself.

“You are my today and all of my tomorrows.” – Leo Christopher

My sons John, Conrad, and Ian, I love you more than life itself.

Don’t die without embracing the daring adventure your life was meant to be.” – Steve Pavlina

My father, for teaching me to fly and paint air castles; my mother, for being my anchor and keeping me rooted. Thank you.

“Your reality is a reflection of your strongest beliefs.” – Unknown

Dearest Friends, I thank you for your part in my journey, no words can describe my gratitude.

“One of the most beautiful qualities of true friendship is to understand & to be understood.” –

Lucius Annaeus Seneca

Lord Jesus Christ I was led by Your grace.

“Looking behind I am filled with gratitude. Looking forward I am filled with vision. Looking upwards I am filled with strength.” – Quero Apache Prayer

Personal note:

“I am driven by two philosophies: Know more about the world than I knew yesterday, and lessen the suffering of others. You’d be surprised how far that gets you.” – Neil deGrasse Tyson

DEDICATION

I dedicate this thesis to all women living with breast cancer.

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*“As a writer you are trying to listen to what others aren’t saying...
and write about the silence” – N. R. Hart*

CHAPTER 1

INTRODUCTION

1.1 Background

Globally cancer incidence is escalating because of population growth and aging, urbanization and economic development (Torre et al., 2015). Cancer continues to be one of the world's primary causes of morbidity and mortality (Torre et al., 2015; World Health Organization, 2015). It is estimated that there will be 20 million new cases by 2020 of which more than 70% will arise in low- and middle-income countries (Kanavos, 2006; Mellstedt, 2006; WHO, 2015). Continents such as Africa, Asia and Central and South America account for more than 60% of annual new cases universally, and 60 to 70% of the world's cancer deaths occur in these regions (Edib et al., 2016; Sambo et al., 2012; WHO, 2015).

Doumit and colleagues (2017) reported, "Breast cancer is responsible for the most frequent malignancy-causing deaths and cancer-related mortality and morbidity in women, an epidemiological profile mirrored in almost every country" (p.21), including South Africa (Apffelstaedt, 2016; Brown & Swartz, 2012; Edge et al., 2014). The accurate pervasiveness of breast cancer in South Africa is not known because of critical resource limitations, such as political and financial constraints encountered by the National Cancer Registry (Edge et al., 2014; Grassi & Watson, 2012; Singh et al., 2014). The most recent data from the South African National Cancer Registry available is the 2010 report showing that breast cancer accounts for 20,62 % of cancer amongst women (Herbst, 2015). According to Herd and colleagues (2015), the National Cancer Registry of South Africa estimates a one in 32-lifetime risk of developing the disease.

1.2 Problem statement

Breast cancer incidence in South Africa appears to be rising on account of increased longevity and urbanization (Brinton et al., 2014; Herd et al., 2015). Edge and colleagues (2014) stated that breast cancer and breast cancer-related complications are one of the most common causes of cancer death in South Africa and despite this information, breast cancer has not been awarded the necessary acknowledgment and apportion of resources. According to Edge and colleagues (2014), the healthcare system in South Africa reflects components of both high-income and low-income countries. “The South African health system has been described as a two-tiered system divided along socioeconomic lines” (Republic of South Africa Health Department, 2015, p.1). Vast differences in the socio-economic environment of private and public healthcare, as well as inconsistent standards throughout the country, have been reported (Young, 2016). These differences include healthcare expense, wait times, general hygiene (glove usage, hand washing, sanitized medical instruments and bed linen), home visits and pharmaceutical availability (Young, 2016). The socio-economic environment includes factors such as health status, employment, education, income and financial constraints (Akinyemiju et al., 2016).

South Africa is ranked, according to the World Bank Classification, as a middle-income country with a Gross Domestic Product (GDP) per capita of more than \$1,045 but less than \$12,736 per year. This refers to a monthly income of more than R1 132.08 but less than R13 797.34 (ChartsBin statistics collector team, 2016). According to Paul Egan, a consultant at Unilever Institute, 70% of the South African population still lives in households earning less than R6000 a month (BusinessTech, 2016). This figure indicates low-income status and poverty. The disparities in wealth constitute a major challenge to healthcare and socioeconomic development.

The healthcare system in South Africa faces, therefore, numeral challenges such as low socioeconomic status, lack of education, unemployment and lack of income. According to Newman (2005), a significant percentage of differences in breast cancer outcomes are probably

the result of socioeconomic circumstances namely, poverty, lack of medical insurance and the need to rely on public and government assistance. In addition to these practical concerns, breast cancer patients encounter emotional and psychosocial needs (Schmid Büchi, 2010).

Lack of, or limited, psychosocial support services together with poor socioeconomic circumstances could attribute to women's deferment of breast cancer diagnosis and treatment, and eventually premature death (Institute of Medicine and National Research Council of the Academies, 2004; Newman, 2005). Edge and colleagues (2014) reported that improvement in breast cancer mortality figures in South Africa would only occur provided that all healthcare and other practitioners employ a truly multidisciplinary approach.

1.3 Research rationale

Goodfield's statement of 37 years ago is currently still applicable and true: "Cancer begins and ends with people. In the midst of scientific abstraction, it is sometimes possible to forget this one basic fact." (Goodfield 1975 as cited in Naidu, 2012, p. 79). Research pertaining to psychological stress and adjustment, done by Schlebusch and colleagues in 1989, 1993, 1998 and 1999, respectively, showed the scarcity of information concerning the psychological experience of breast cancer in South Africa. However, despite recommendations over the years to pay more attention to patients' experiences and psychosocial concerns (IOM, 2008; Schlebusch, 1998) little in-depth qualitative research pertinent to psychosocial concerns and needs affiliated with breast cancer diagnosis and treatment have been conducted (Beatty et al., 2008).

The rationale for this study is to address the gap pertaining to knowledge of psychosocial concerns and needs presently existing in breast cancer care between biomedical treatment as provided by clinicians and how women process the experience of breast cancer from diagnosis, throughout treatment, and into survivorship. A possible means through which to address this gap is to adhere to personal narratives from this patient group living with breast cancer. This is in keeping with current trends in qualitative research, where in-depth narratives are the bridge

between theory and practice. In-depth narratives allow women to become active participants in their own care rather than mere receivers of care.

Therefore, this study endeavors to explore the experiences (diagnosis and treatment) of women living with breast cancer, and highlight the importance of involving patients in their own care. Patient involvement is to allow breast cancer patients to participate in decision-making and share their personal experiences (Vahdat et al., 2014). Involving patients in shared decision-making regarding treatment and health care delivery is to recognize and respect each woman's unique perspective on their own life and to highlight their responsibility towards healthy lifestyle choices (Entwistle, Brown, Morgan, & Skea, 2014).

Limited South African research is available on diagnosis- and treatment-related experiences of women attending public health breast cancer clinics. Tsianakas and colleagues (2012) argued that patients' experiences are fundamental in evaluating the quality of health care. Patients' experiences provide an in-depth understanding of the meanings patients adhere to psychosocial concerns associated with breast cancer. Adherence to psychosocial concerns and needs pertaining to each individual patient is likely to enhance adaptive psychological experiences to diagnosis, treatment consequences and recovery (Pidlyski et al., 2014; Schmid-Büchi et al., 2008).

Provision of psychosocial counseling and support services as part of a multidisciplinary approach to breast cancer care is therefore particularly relevant to this patient group receiving diagnosis and treatment (Beatty et al., 2008; Edge, 2014; MacLaughlan & Dizon, 2009; Ristevski et al., 2014). At the present time, no formal psychosocial counseling service is available at the Breast Clinic for patients to attend after receiving the diagnosis from the clinician (K. Baatjes, February 12, 2016, personal communication).

The findings of the present study generated an informed understanding and recognition of the experiences of breast cancer diagnosis and treatment. The findings can facilitate the

improvement of treatment interventions, as well as reinforcing policy development regarding routine multidisciplinary care for breast cancer patients.

1.4 Research question

My intention with this study was to understand what it means to receive a breast cancer diagnosis and treatment and gain firsthand knowledge of women living with the disease. The research question for this study was: “What are the subjective experiences of breast cancer patients receiving diagnosis and undergoing treatment?”

1.5 Research aim and objectives

The primary aim of the study was to investigate and interpret the subjective psychosocial experiences of breast cancer patients receiving diagnosis and undergoing treatment. The study explored and described participants’ understanding of breast cancer. This study aimed to recognize and partially fill the gap that currently exists in the South African literature pertaining to subjective experiences of breast cancer.

The objectives of the study were to 1) understand the subjective psychological experience associated with breast cancer diagnosis and treatment, 2) elucidate the subjective physical experience associated with cancer treatment and management, 3) explore specific perceptions and psychosocial needs of breast cancer patients and 4) identify meaning-making in breast cancer. This study emphasized the humanistic value of patient’s narratives and researcher interpretations of the lived experience of breast cancer patients and their families as a critical part of health care and medical treatment across the cancer journey.

1.6 Thesis Layout

The present study is part of a larger study regarding breast cancer. This thesis consists of eight chapters. Chapter 1 provides the background for the study, as well as a discussion of the

research rationale and research aim and objectives. Chapter 2 is a discussion of contemporary literature pertaining to perceptions of breast cancer, the subjective experiences of breast cancer patients receiving diagnosis and treatment, as well as meaning-making and coping. Chapter 2 also discusses the theoretical frameworks supporting this study.

Chapter 3 explains the research methodology, including the research design, the research setting, a description of the participants and recruitment procedure, as well as data collection and data analysis. Data collection is qualitative by means of semi-structured interviews with an emphasis on Interpretative Phenomenological Analysis (IPA) as the method of choice. Interpretative Phenomenological Analysis aims to substantiate the participant's 'sense-making' (emic perspective) of the experience, as well as the researcher's 'sense-making' (etic perspective) of the participant's perspective (Pietkiewicz & Smith, 2014). Reflexivity will also be discussed in Chapter 3. In Chapters 4 to 6, I present the findings of Lily, Mina and Ester's case studies, respectively. The findings reflect each woman's unique experience with breast cancer and highlight the idiographic commitment to the study. Chapter 7 provides a discussion of important findings, as well as similarities and differences across the three case studies. Chapter 8 includes a conclusion, limitations of the present study and recommendations for future research.

1.7 Conclusion

Chapter 1 provided an introduction to the present study regarding the subjective experiences of breast cancer patients receiving a diagnosis and treatment. Emerging data show the incidence rate of breast cancer to be a global concern. Studies have shown that all women are exposed to the possibility of developing breast cancer. Breast cancer impacts on a physical, emotional, psychological, social and practical level with expansive consequences. This chapter provided an overview of the background of cancer and more specifically breast cancer. This chapter also described the research rationale, research aim and the organization of this thesis.

CHAPTER 2

LITERATURE REVIEW AND THEORETICAL FRAMEWORK

2.1 Introduction

This literature review provides a structured and logical discussion of topical literature, as well as older landmark studies, pertaining to women's subjective experiences of breast cancer. Subjective experiences include emotional, physical, psychosocial and meaning-making responses to breast cancer diagnosis and treatment. The search revealed numerous findings and results from both quantitative and qualitative research.

In keeping with the aim of this study on the subjective experiences of South African women receiving breast cancer diagnosis and treatment, I conducted an extensive literature review, including studies from across the world and South Africa. Numerous studies on the subject were available, but South African studies were limited. More importantly, no case studies employing Interpretative Phenomenological Analysis were found on South African women's subjective experiences of breast cancer diagnosis and treatment.

I commence by defining and discussing key terminology. Important to note, the primary aim of this chapter is an in-depth discussion of subjective experiences of breast cancer diagnosis and treatment. In view of the primary aim, I decided to start with a discussion on perceptions of breast cancer. Perceptions ultimately influence experiences of breast cancer diagnosis and treatment. Therefore, I consider this to be an important aspect of the discussion. Following is the in-depth discussion of diagnosis and treatment experiences.

A section, research authentication, provides valid situated information with regard to the research question of this current study, within the context of (limited) existing qualitative South African research on this subject. Following is a section on meaning-making and coping, which first, is an integral part of breast cancer experiences, and second, reflects the principles of the

chosen methodology, Interpretative Phenomenological Analysis. The final section of this chapter includes concluding remarks and a discussion of theoretical frameworks, namely Self-in-Relation theory, the Biopsychosocial Spiritual model, and Constructivism.

2.2 Key terminology

The following terms and concepts will frequently be used throughout the entire thesis: 1) breast cancer, 2) lifestyle factors and choices, 3) disease and illness, 4) chronic disease and chronic illness, 5) survivorship, 6) psychological distress, 7) a sense of identity and 8) needs of breast cancer patients.

2.2.1 Breast cancer

A breast is a specialized gland consisting of 15 to 20 lobules, ducts and tissue elements (Nawaz, 2011). Breast tissue elements and cells can act responsively or unresponsively to hormonal changes occurring over time. These changes can be non-malignant, atypical or cancerous (Nawaz, 2011). Changes in breast appearance include a hard, irregular lump in the breast that could be tender but not painful, unusual nipple discharge (e.g. a spontaneous blood-stained excretion), changes in nipple appearance (e.g. inverted nipples), change in the skin of the breast (e.g. thickening and /or dimpling as well as redness, swelling and itchiness), changes in breast size and an axillary lump or swelling (Eedes, 2011; Nawaz, 2011).

2.2.2 Lifestyle factors and choices

Breast cancer is associated with a westernized lifestyle (Apffelstaedt, 2016; Argolo, Hudis, & Iyengar, 2016; Arnold, 2016; Derman et al., 2009; Porter, 2008). 'Westernization,' according to Porter (2008), refers to improved socio-economic circumstances, allowing women reproductive control and the adoption of less sensible dietary and exercise practices, all of which enhance breast cancer risk. Lifestyle choices are often influenced and determined not only by socio-economic

factors, but also cultural beliefs and traditions, e.g., traditional healers and geographic availability of oncological health care services (Vorobiof, Sitas, & Vorobiof, 2001).

2.2.3 Disease and illness

Description of the terms ‘disease’ and ‘illness’ as heretofore argued by Kleinman (1988) are still applicable today. Disease refers to dysfunctional anatomical organs and structures as seen through the scientific lens of modern medicine, with growing dependence on iatric (medical) technology (Carel, 2016). Disease, from the perspective of the practitioner, is a conservative reconstruction of a person’s illness (Kleinman, 1988 as cited in Gabrielsen, Nåden, & Lindström, 2014). According to Gabrielsen and colleagues (2014), Kleinman described illness as fundamentally different to disease as the former is the individual’s perceptions and reactions to symptoms and suffering. Illness, as used in the context of this study, referred to the particular lived experiences of breast cancer and as a result, the critical and life-changing conditions that could facilitate complete transition and adjustment, in and of a woman’s life (Carel, 2016; Larsen, 2009).

This transition (human experience) from health to illness is more than solely physical or mental impairment (Carel, 2016). It demands an altered view of personal identity, which contains the disintegration of meaning, as well as altered potential and expectations (Carel, 2016; Larsen, 2009). Toombs (1993, as cited in Carel, 2016) described five features of illness, all of which pertain to a sense of personal identity, namely: “The perception of loss of wholeness, loss of certainty, loss of control, loss of freedom to act and loss of the familiar world. These losses represent the lived experience of illness in its qualitative immediacy” (p. 43).

2.2.4 Chronic disease and chronic illness

Chronic disease is explained in terms of the biomedical disease classification whereas chronic illness refers to the particular experience of living with the adversities that are affiliated

with chronic disease (Martin, 2007). Chronic illness, especially in the context of this study, has been described as a “biographical disruption” (Bury, 1982 as cited in Sarenmalm et al., 2009, p. 1117) and as “loss of self” (Charmaz, 1983, as cited in Sarenmalm et al., 2009, p. 1117).

Cancer was previously perceived as an acute disease and synonymous with dying (Olsen, 2016; Tritter & Calnan, 2002). However, due to advanced diagnostic and treatment interventions, the number of cancer survivors is increasing, as well as their lifespan (McCann, Ilingworth, Wengström, Hubbard, & Kearny, 2010; Sherman, Rosedale, & Haber, 2012). Therefore, cancer has recently been conceptualized as a chronic disease (Brennan, 2014; Sherman et al., 2012).

Various definitions of chronic disease include explanations such as disruption of life-course (McCann et al., 2010), a lasting and indefinite affliction (Adler & Page, 2008), as well as a profound and lifelong change to the body (Carel, 2016). According to Centers for Disease Control and Prevention, ‘chronic’ entails managed but not cured (Ford, 2015). The ‘chronic illness’ description of breast cancer, and by implication, prolonged survival, encompasses physical, emotional, psychological and social challenges for women living with this incessant condition (Larsen, 2016; Manicom, 2010).

2.2.5 Survivorship

Breast cancer survival conveys the idea of living with a chronic and intricate condition (Phillips & Currow, 2010; Sherman et al., 2012). A person living with cancer is considered to be a survivor from the time of diagnosis until death (National Cancer Institute, 2009 as in Waldrop, O.Conner, & Trabold, 2011). An in-depth discussion of survivorship is not within the scope of this study.

2.2.6 Psychological distress

Historically, issues in cancer care were defined in terms of physical symptoms and clinical results. However, reports from the Institute of Medicine (now the National Academy of Medicine), in 1999 and the landmark 2008 report, as well as recommendations from the

International Psycho-Oncology Society, have emphasized the importance of psychological distress as the sixth vital sign in routine cancer care (LeBlanc & Kamal, 2017; Mitchel, 2014).

A definition of psychological distress comprises emotional (perceptual and cognitive), intellectual, physiological and instrumental aspects that surpass psychiatric diagnosis of major depressive disorder or mood (anxiety) disorder (Ganz, 2008; LeBlanc & Kamal, 2017; Ohaeri, Ofi, & Campbell, 2012; Sheppard et al., 2014). Emotional aspects of psychological distress that are specific to cancer include fear of recurrence, anxiety related to follow-up medical consultations, vulnerability, lack of self-worth, invasive thoughts of death and social isolation (Aaronson et al., 2014; Ganz, 2008; Holland, 2004; Ohaeri et al., 2012), as well as internalized stigma (Waite, Knight, & Lee, 2015).

2.2.7 A sense of identity

A sense of identity, as defined by Nugent (2013), refers to being mindful (conscious) of inner experiences and extrinsic events, as well as being a distinguishable individual. As distinguishable individuals, we have features and elemental qualities, as well as social representation within social roles and relationships (Oyserman, Elmore, & Smith, 2012). These features, also known as identities, describe our self-concept and are not permanent; rather they are characterized by constant change and activity (Oyserman, Elmore, & Smith, 2012). It is also important to note that these features (identities) of self-concept are socio-culturally constructed (Breakwell, 2010; Glynn, 2006; Lipps, 2006). Self-concepts are described as basic mental processes that can differ in structure and are used for meaning-making, self-monitoring and protection of self-worth (Breakwell, 2010; Oyserman et al., 2012).

Findings from a study conducted by Chen and colleagues (2016), indicated that self-concepts, as well as representations of others, are not merely a list of characteristics and social categories. Rather, different self-concepts have different focal points, such as the past, present or future and as individuals, we can dwell in the past, or focus on the present truth (Chen et al., 2016;

Oyserman et al., 2012). Both are familiar concepts and can be explored and explained (Chen et al., 2016; Oyserman et al., 2012). Thinking about the future, however, often creates trepidation pertaining to meaning-making, expectations, unidentified obligations and uncertainties (Oyserman et al., 2012). Irrespective of the individual's focal point, according to Oyserman and colleagues (2012), people often draw on autobiographical memories to ensure a feeling of knowing (themselves). This feeling of knowing is pivotal to the woman's perception, meaning-making, decision-making and self-regulation as it pertains to her personal identity (Oyserman et al., 2012; Schulzke, 2011).

Noteworthy, at this point, are social constructions of breast cancer as these directly influence meaning making, self-regulation and coping strategies. Social constructions refer to individuals' unique perceptions of the world and their particular experiences in constructing their realities (Quest, 2014). According to Mermer and colleagues (2016) and Schulzke (2011) contemporary social constructions and social interpretations are influenced by the social context of these women and revolve mainly around body image, femininity, physical appearance, self-worth, aesthetics, identity and self-concept. Social constructions undisputedly influence breast cancer experiences, moreover, it greatly impact on women's personal identity.

The concept of personal identity gradually and continuously develops over time (Chen et al., 2016). It includes logical and consistent memory, norms for behavior, moral qualities and social categories (Chen et al., 2016; Darity, 2008; Glynn, 2006). These characteristics of a sense of identity and, therefore personal identity, are undeniably disrupted by illness (Carel, 2016) and are critical aspects of breast cancer experiences. Price Herndl (2006) highlighted the existential crises often faced by breast cancer patients with the clearly stated question posed by this patient group "Who am I now?" (p.222). This question encompasses the essence of breast cancer illness as it pertains to personal identity. The disruption caused by illness significantly impacts on

physical and cognitive capacities, resulting in adjustments which ultimately impacts on personal identity (Carel, 2016; Wolf, 2015).

According to John Kubie, a neuroscientist at Downstate Medical Center New York, the concept of personal identity consists of six components, namely “autobiographical identity, body identity, sense of agency, social identity, beliefs and conscious identity” (Kubie, 2014, para. 2-6). In the next paragraphs, I describe each of these components.

Autobiographical identity: Autobiographical identity refers to the construction of the self by means of lived narratives (Kubie, 2014). These lived narratives consist of reconstructed stories of the past combined with future expectations and visions in order to provide present life with purpose and worldly continuity (McAdams, 2017).

Body identity: Kubie (2014) defined body identity as follows: “My body is the boundary of myself. I am what is within my skin. I have a ‘feeling’ of my body, that is me” (para. 2). Female body identity is inseparably connected to femininity and women’s perspectives of attractiveness, which include physical appearance and characteristics such as body shape, hair color, weight, facial features and breast size and shape (Helms, O’Hea, & Corso, 2008; Moreira, Silva, & Cabavarro, 2010). The breast is not seen as merely another body part, according to Levin (2006), it is regarded as the ultimate representation of female sexuality, as well as nurturance, motherhood, and womanhood.

Sense of agency: Sense of agency reflects an individual’s capacity for effective and responsible intervention strategies along with a strong belief in personal physical abilities, as well as social abilities (Kubie, 2014; Moore, 2016). Sense of agency refers to a person’s power to influence or direct actions and the consequences of those actions (Haggard & Chambon, 2012; Moore, 2016).

Social identity: Social identity refers to the connection a person feels she has with a group as well as the specific role the person assumes within the group (Kubie, 2014). Group interaction

is a necessary aspect of social identity (Breakwell, 2010). Groups include family, social networks, occupational environment, sport and recreation and religious affiliations, to name a few (Kubie, 2014). Social identity reflects, therefore, different representations of the self within the societal structures that represent the social context (Breakwell, 2010).

Beliefs: Kubie (2014) uses the term ‘beliefs’ to explain a relatively stable structure of our knowledge about the world and ourselves. Kubie (2014) also based his description on Bayes’s theory, which draws on three core principles of beliefs. First, any conclusion and experience have various explanations (Sotala, 2010). Secondly, present and future interpretations of events and experiences are dependent on prior (already existing) knowledge (Kubie, 2014; Sotala, 2010). Thirdly, beliefs are subjective (instinctive and personal) and may change slowly over time (Kubie, 2014; Sotala, 2010).

Conscious identity: Conscious identity as described by Kubie (2014): “I am the author of my subjective experience... also called conscious agency” (para. 6). Conscious identity refers, therefore, to a person’s internal capacity to administer and control awareness and responsiveness (Kubie, 2014). Upon receiving a formal diagnosis of breast cancer the woman’s personal identity, including all the components mentioned above, change irrevocably. This change also referred to as a “biographical disruption,” encompasses various alterations to a woman’s sense of self (personal identity) and future direction (Olsen, 2016, p.17). This biographical disruption often leads to the labeling of women diagnosed with breast cancer as ‘cancer patients,’ which reflects a changed identity (Olsen, 2016).

2.2.8 Needs of breast cancer patients

Prior and contemporary research has shown that breast cancer patients have particular psychological and social needs (Cheng et al., 2013; Ohaeri et al., 2012; Pidlyski et al., 2014; Schmid-Büchi et al., 2008) as well as practical, physical and informational needs (Beatty et al., 2008). Fulfillment of these needs, pertaining to each individual patient, is necessary in order to

increase adaptive psychological experiences with regard to diagnosis, treatment results, and adjustment (Pidlyski et al., 2014; Schmid-Büchi et al., 2008).

Schmid Büchi (2010) described a need as an internalized compulsion that motivates goal achievement behavior and well-being. Breast cancer diagnosis and treatment present a particular challenge to well-being, goal achievement behavior, and fulfillment of needs of a particular individual (Liamputtong & Suwankhong, 2016; Schmid Büchi, 2010).

Individual and cultural factors that might influence a patient's psychosocial needs and responses are e.g. the patient's age, stage of cancer, social support and the intensity of psychological distress experienced (Bloom et al., 2012; Iwatani et al., 2013; Knobf, 2015), as well as individual coping strategies and personal circumstances (Institute of Medicine (IOM), 2008; Kim, Han, Shaw, McTavish, & Gustafson, 2010; Marlow, 2003). I shall describe these needs in relation to breast cancer in the following paragraphs.

Biological and treatment-related needs: Biological and treatment-related needs refer to physical aspects associated with breast cancer, namely disfigurement, scarring, physically challenging interventions and complications, cognitive impairment (attention and concentration), pain, fatigue and functional disabilities, other chronic illnesses e.g. cardiovascular disease (Aaronson et al., 2014; Adler & Page, 2008; Ganz, 2015; Pidlyskyj et al., 2014), menopausal problems e.g. hot flushes, diminished libido (Braybrooke et al., 2015), and sleep disturbance e.g. recurrent nightmares (Ganz, 2008; Schmid Büchi et al., 2008). With regard to physical symptoms, Ganz (2015) and Aaronson and colleagues (2014) reported younger westernized women to have more intense experiences related to fatigue and bodily pain.

Emotional and psychological needs: Emotional and psychological needs and issues, such as body image, femininity, loss of sense of desirability and sexuality could be a direct complication of specific physical problems (Ganz, 2008; Schmid Büchi et al., 2008). Findings pertaining to body image included reports on appearance issues, disfigurement, low-self-esteem

issues and self-consciousness in public (Przezdziecki et al., 2013; Schmid Büchi et al., 2008).

These findings are in keeping with current psychosocial needs surrounding physical issues and bodily adjustment (Aaronson et al., 2014; Ganz, 2015; Pidlyskij et al., 2014).

Additional psychological needs and problems included loss of sense of agency (autonomy and competence), role limitations, anxiety, fear, and psychological distress (Ganz, 2008; Hull et al., 2016; Schmid Büchi et al., 2008), feelings of guilt and anger, adjustment disorders and post-traumatic stress disorder (Adler & Page, 2008).

Informational and support needs: Informational and support needs reflected the women's (80%) constant requirement for information pertaining to treatment and side effects, alternative and self-help interventions as well as remission and mortality (Adler & Page, 2008; Schmid Büchi et al., 2008). A critical factor mentioned was the manner of conveyance by the clinician and healthcare personnel of this life-changing information. Communication difficulties result in diminished emotional and social well-being (Schmid Büchi et al., 2008).

Psychosocial needs: Psychosocial needs include social support requirements of the patient's partner, family and care providers (Ohaeri et al., 2012; Schmid-Büchi et al., 2008), as well as affordable (and available) multidisciplinary care for the patient and the family (Beatty et al., 2008; Iwatani et al., 2013). Adler and Page (2008) report additional social needs and problems, which include financial stress, lack of (or inadequate) health care insurance, reduced employment, lack of transportation and weak social support, as well lack of support from the health care system.

It is evident from the existing literature that women living with breast cancer have specific psychosocial needs. Unmet needs (or perceived unmet needs) have a profound psychological and physical impact on women's subjective experiences of breast cancer diagnosis and treatment, and ultimately, quality of life (Palmer et al., 2016; Park & Hwang, 2012). For the purpose of this study I am only reflecting on women's psychosocial needs, but would recommend the inclusion of relative's needs for future research studies for the mere fact that it is evident that breast cancer is a

family matter, and breast cancer diagnosis and treatment affect the entire family (Adler & Page, 2008; Manicom, 2010).

2.3 Perceptions of breast cancer

A woman's perception, understanding, and beliefs with regard to breast cancer may influence her experience of breast cancer diagnosis and treatment (Heggenstaller, 2013; Henriksen, Guassora, & Brodersen, 2015; Mermer, Nazli, & Ceber, 2016; Mosavel, Simon & Ahmend, 2010; Nkala, 2014). In the context of this study, exploring existing literature regarding women's perceptions of breast cancer is fundamental to my understanding of women's particular breast cancer experiences.

According to Kleinman's Explanatory Model of Health, disease, and illness, people's individual beliefs, expectations and (lack of) knowledge about sickness (breast cancer) were shown to influence coping and compliance (Donnelly et al., 2013; Mosavel et al., 2010). Moreover, the model recognizes that individual perspectives have to be interpreted with cognizance of specific sociocultural backgrounds (Donnelly et al., 2013; Inan et al., 2016; Lee, 2015).

Findings from a quantitative study conducted by Donnelly and colleagues (2013) with 1,215 self-identified Arabic women revealed that, despite living with breast cancer, 76,2 % of the participants reported exceptional health. However, social stigma, values, and attitudes have been found to influence beliefs pertaining to causality, which included fatalism, family history, no breastfeeding and an unhealthy lifestyle (Donnelly et al., 2013). In a review regarding cultural factors associated with cancer, the following significant cultural factors were highlighted: relatives, humiliation and shame, lifestyle, fatalism (most mentioned), adjustment to culture and health information, e.g., women admitted that no symptoms mean no illness (Lee, 2015; Mosavel et al., 2010).

Obikunle (2016) reported similar findings generated from an Interpretative Phenomenological Analysis with 14 African American women living in an urban region. In addition, she reported that the participants' level of education and communication skills, mistrust and lack of knowledge as well as financial constraints, had a significant impact on their perceptions of breast cancer. Lack of knowledge, including lack of knowledge pertaining to the causality of breast cancer, appears to be an important factor as this was also found in a study conducted with rural women and urban middle-class women in Kenya (Muthoni & Miller, 2010). Moreover, discrepancies were found pertaining to causes of breast cancer among rural women and urban middle-class women. Findings from the study conducted by Muthoni and Miller (2010) with eight focus groups (four with rural women and four with urban women), revealed three important causal categories, namely lifestyle and physical aspects, malediction (curses) and hereditary factors.

Urban women appeared more informed regarding lifestyle factors as probable causes of breast cancer, whereas rural women disclosed their beliefs pertaining to their breast cancer causality as the result of breast milk retention due to early discontinuation of breastfeeding, carrying money or mobile phones between breasts, wearing too small underwear (bra), as well as witchcraft, curses and punishment from the ancestors (Bettencourt, Schlegel, Talley, & Molix, 2007; Muthoni & Miller, 2010). Both rural and urban low-income women admitted to non-adherence of breast examinations in the absence of signs and symptoms (Muthoni & Miller, 2010).

As deduced from the above-mentioned studies, and subsequent research, it is clear that social and religious customs, mythology, as well as cancer-associated stigmatization, are still prevalent globally, irrespective of culture and religion (Daher, 2012; Gullatte et al., 2010; Wagstaf, 2013). Mythology-comprised beliefs concerning cancer, such as being contagious and an

act of punishment, often enhanced stigmatization and the proverbial silencing of the disease (Daher, 2012; Inan et al., 2016).

Findings from a survey ($N = 4500$) conducted by LIVESTRONG suggested that cultural myths and fears caused by misinformation and lack of awareness, as well as stigmatization were deeply established across countries, cultures and communities (LIVESTRONG, 2007; Redmond & Wagstaff, n.d., slide 32; Wagstaff, 2013).

The studies and literature reviews mentioned show similar evidence regarding social context as having a deep-seated influence on the lived experience of breast cancer. Perceptions of living with breast cancer are subjected to contending social interpretations that exist within the different cultures (Ramathuba, Ratshirumbi, & Mashamba, 2015). South Africa is known to have a demographically and culturally diverse population, but intercultural differences regarding perceptions of breast cancer still lack research (Rayne et al., 2017).

Results from an exploratory, descriptive study with 100 predominantly colored women living in a challenging socio-economic environment near Cape Town, South Africa, proposed that the majority of women (76%) knew about lumps and breast cancer (Krombein & De Villiers, 2006). Fear of being diagnosed (87%) was reported as the greatest barrier to seeking health care interventions, whereas lack of knowledge accounted for only 20% (Krombein & DeVilliers, 2006). Mosavel, Simon, and Ahmed (2010) reported similar fear-based results from their South African study with 157 mother and adolescent daughter pairs. In addition, even though the women were aware of the possibility of breast cancer they declared themselves risk-free and healthy in the absence of signs and symptoms (Lee, 2015; Krombein & De Villiers, 2006; Salant et al., 2006).

Yet, research conducted by Ramathuba and colleagues (2015) in rural Limpopo province, with 150 Tsivenda-speaking women, aged between 30 – 65 years, suggested ignorance and lack of knowledge regarding breast cancer to have a significant impact on health behaviors. One hundred

and four of these women were completely uninformed (Ramathuba et al., 2015). Most perceived themselves as not at risk and maintained a negative attitude towards breast cancer, preferring traditional and spiritual healers (Ramathuba et al., 2015). Additional factors impacting on these women's beliefs and attitudes about breast cancer, as identified by Ramathuba and colleagues (2015), included employment status, occupation, poverty, religion, and views from family members. Perceptions of breast cancer were influenced by the women's already existing fatalistic worldview, beliefs in evil spirits and witchcraft, stigmatization due to possible transferability, as well as fear and anxiety associated with screening interventions (Al-Azri et al., 2014; Ramathuba et al., 2015).

Even though Ramathuba and colleagues (2015) reported intercultural differences, findings from the study conducted by Rayne and colleagues (2017) with 259 urban South African women from various demographic and socio-economic backgrounds, suggested minimal independent demographic and socioeconomic variance in beliefs and attitudes about breast cancer. Rayne and colleagues (2017) reported findings of positivity towards a medical cure (87.9%) and family support (90%), as well as spiritual convictions (79.5%). Additional findings reported, included access to information and acquired knowledge enhanced the women's confidence and diminished negative beliefs (Rayne et al., 2017).

Globally and in South Africa, perceptions surrounding breast cancer are inextricably connected to women's particular sociocultural background, including their beliefs, attitudes, and behavior towards health and illness, as well as potential and perceived barriers. Extensive research with regard to perceptions of breast cancer has been conducted globally, but only a few South African studies were found. In view of this, I recognized a gap in the literature on South African women's perceptions of breast cancer, especially in the light of our diverse socio-cultural backgrounds and socio-economic circumstances. A second gap in the literature refers to limited research on the actual effect of those perceptions on the breast cancer illness trajectory. The

literature reviewed indicated the significant impact of perceptions of breast cancer on the actual experiences associated with breast cancer diagnosis and treatment.

2.4 Subjective experiences of breast cancer diagnosis and treatment

2.4.1 Breast cancer diagnosis

Background: From the above-mentioned literature, regarding women's psychosocial needs and perceptions of breast cancer, it is established that both concepts impact greatly on women's experiences of breast cancer diagnosis and treatment. Notwithstanding contemporary medical advances in cancer care and global reports on the longevity of cancer patients, a cancer diagnosis is still tantamount to a death sentence (Al-Azri et al., 2014; Inan et al., 2016; Mosavel et al., 2010; Naidu, 2012; Olsen, 2016).

Existing literature (qualitative and quantitative) on breast cancer diagnosis reported extensive negative psychological consequences for the patient and the patient's family, predisposing both to negative psychosocial experiences (uncertainties), emotional challenges and deficient adjustment (Boinon et al., 2014; Ohaeri et al., 2012; Strauss, 2014). Emotional challenges include fear, sorrow, unpredictability, anxiety, anticipatory grief, complicated grief, shock, indignation, and distress regarding body image and sexuality (Overton & Cottone, 2016; Shear, 2015; Strauss, 2014). These emotions are never experienced in isolation, rather, they are intricately connected (Strauss, 2014). Beatty and colleagues (2008) reported similar findings from their Australian study (mentioned before), showing an incidence rate as high as 56% of women experiencing emotional adjustment problems as a result of the direct impact of breast cancer diagnosis.

In view of the above-mentioned literature and prior to my descriptions in a more structured review, I conclude it critical to define the following processes, namely existential plight, transformative experience, and liminality. These processes emphasize the intensity of a breast

cancer diagnosis experience. In the context of this study, a deep understanding of the experience associated with breast cancer diagnosis would certainly enhance the interpretation of this experience.

Existential plight: According to Kernan and Lepore (2009), breast cancer patients experience an existential plight, which consists of emotional obligations, health concerns and continuous thoughts regarding mortality. Therefore, receiving a diagnosis of breast cancer is a stressful and transformative experience (Carel, 2016; Inan et al., 2016), also considered the pivotal moment in which a woman's reality, as known to her, is irrevocably altered (Olsen, 2016; Price Herndl, 2006; Schweitzer et al., 2012; Sherman et al., 2012). According to Carel (2016), the moment a diagnosis is received is also the moment in which the illness is noted by others and acknowledged by the ill person as disease.

Transformative experience: This transformative experience encompasses a series of existential events (disrupted regular practices, abilities and expectations), which surpasses physical and mental dysfunction, often resulting in the disintegration of meaning structures (Carel, 2016; Ng et al., 2017) and quality of life (Mehrabi et al., 2015). According to Kyriakides (2015), a diagnosis of breast cancer elicits uncertainties and psychosocial needs that embody the patient's and the family's life and reality. This statement was supported by the findings from the research conducted by Inan and colleagues (2016), in which nine Turkish women reported ongoing uncertainties and questions regarding the disease, the treatment and how the illness will influence their social relationships.

Liminality: In addition to the transformative nature of a breast cancer diagnosis, Koutri and Avdi (2016) introduced the idea of liminality. They suggested that from the moment of diagnosis, patients enter a liminal space (transitional period) that might, for some, last throughout their lives. According to Koutri and Avdi (2016), the assumption of liminality focuses on the ambiguity an individual experience within the transitional period between health and illness.

Therefore, a diagnosis of breast cancer imposes a challenge to women, their partners and their families to reassess their behavior, motives, needs and coping strategies (Emanuel, Johnson, & Taromino, 2017; Fergus & Gray, 2009; Holland et al., 2015). Reacting to these challenges is personal and unique to each individual woman (Kaptein et al., 2015), often resulting in (self-imposed) social isolation (Al-Azri et al., 2014; Banning, 2014).

Structured review: Findings from a qualitative study conducted with 19 Arabic women (Al-Azri et al., 2014), reflected similar findings to the research of Beatty and colleagues (2008). In addition, Al-Azri and colleagues (2014) reported findings, which included women's disbelief, fear of death, self-blame, low self-esteem and false self-perception. Supplementary to these responses and challenges mentioned above, receiving a breast cancer diagnosis may also elicit shock (Breitbart & Alici, 2009; Fu, Xu, Liu, & Haber, 2008; Liamputtong & Suwankhong, 2016), surprise a changed perception of self (Lindwall & Bergbom, 2009), denial, and therefore delay in treatment initiation (Gullatte et al., 2010; Jones et al., 2010; Watson, Greer, Blake, & Shrapnell, 2006), fear of death, and fear of recurrence (Butow, Fardell, & Smith, 2015; Holland, 2004; Ozakinci et al., 2014), loss of sense of belonging (Naidu, 2012), as well as loss of control, disbelief, despair and self-blame (Liamputtong & Suwankhong, 2016).

Research findings from a phenomenological study done with Chinese breast cancer patients revealed that these patients also experienced feelings related to distress e.g., fear, stress, worry, regret, depression, and sadness (Fu et al., 2008). Distress is a comprehensive term referring to various psychological, social and spiritual aspects affiliated with breast cancer (Fu et al., 2008; Lindwall & Bergbom, 2009; Pargament, 2015; Roy-Byrne, 2014). Iwatani and colleagues (2013) conducted a longitudinal study with 222 Japanese patients to explore psychological distress related to the diagnosis of breast cancer and found that approximately 20-40% of patients indicated psychological distress. Similar findings were reported from a quantitative study conducted with 150 Portuguese breast cancer patients (Den Ouden, 2009; Tojal & Costa, 2015). These findings

revealed that breast cancer patients could be at risk for psychiatric symptoms such as depression, anxiety as well as, feelings of hopelessness and helplessness (Tojal & Costa, 2015).

Psychological and emotional experiences, therefore, include the above-mentioned responses, but moreover, psychological experiences include aspects pertaining to a modified sense of self (Denieffe & Gooney, 2011; Lindwall & Bergbom, 2009). Perceptions of self and perspectives on life changed when women were diagnosed with breast cancer (Beatty et al., 2008; Mehrabi et al., 2015; Olsen, 2016). Self-perception might be influenced by the patient's feelings of vulnerability (Janz et al., 2007; Knobf, 2007), feelings of loss of sexual attractiveness and feelings of loss of femininity because of bodily disfiguration (Ohaeri et al., 2012; Strauss, 2014). The above-mentioned altered perceptions regarding femininity, attractiveness and altered bodies will be discussed in detail in section 2.7.

These findings pertaining to breast cancer diagnosis are in keeping with studies done in countries such as United States of America (Begovic-Juhant et al., 2012; McClelland et al., 2015), Japan (Iwatani, et al., 2013), South Africa (Van Oers & Schlebusch, 2013) and Zambia (Maree & Mulonda, 2015) to name a few. Research findings mentioned were from both, smaller qualitative studies and expansive quantitative studies. Even though the findings reported were thorough and explicit, it provided a generalized overview of all the possible psychological and emotional challenges women, globally, experienced. Overall, findings reported similarities in experiences and did not specify particular differences. Moreover, specific individual experiences of receiving a diagnosis of breast cancer were not mentioned.

2.4.2 Breast cancer treatment

Background: In addition to the subjective experiences of breast cancer diagnosis, subjective experiences of breast cancer treatment are as important in the context of this study. A diagnosis of breast cancer necessitates breast cancer treatment (Henriksen & Hansen, 2009). Even though breast cancer treatments are currently considered to be less invasive, it has also increased

in duration and complexity (Ganz, 2008; Naidu, 2012). The complexity of treatment include the combinations of treatment interventions and procedures, number of medical visits, waiting times, multiple care providers, copious decision-making and information overload (Ganz, 2008). The concept of breast cancer treatment, therefore, evokes an intense and critical demand for knowledge and information pertaining to medical interventions (Olsen, 2016; Vogel, Bengel, & Helmes, 2008).

Breast cancer treatment, as also mentioned in the previous section, is a transformative experience consisting of physical, psychological and emotional aspects (Bates, Taub & West, 2016). These aspects pertaining to breast cancer treatment will be discussed in detail in the following paragraphs. For the purpose of this section, the term ‘treatment’ includes chemotherapy, radiation, lumpectomy, mastectomy (single and bilateral), endocrine therapy and medication.

A structured review of physical aspects: Physical aspects of treatment include both long-term side effects and late side effects. Results from a quantitative study with American women ($N = 1372$) reported the following complications with regard to treatment: 1) fatigue (feeling tired and weak, need to rest), 2) systemic side effects (hot flushes, dry mouth, headaches, painful eyes, feeling ill, unusual taste of food, appetite loss, diarrhea, nausea and vomiting, hair loss), 3) sleep disturbances, 4) breast symptoms (pain in breast, breast oversensitive, swollen breast, skin problems), 5) pain with daily activities, 6) arm symptoms (swollen arm, pain in arm and shoulder, difficulty raising arm), 7) dyspnea and 8) menopausal symptoms (Janz et al., 2007). Additional complications included bowel and bladder changes (Bates et al., 2016; Janz et al., 2007), lymphedema and diminished sexual functioning (Janz et al., 2007; Love, Lindsey, & Love, 2015; Winch et al., 2015), as well as medicinal side effects (Knobf, 2015; Pilkington, Rumsey, O’Connor, Brennan, & Harcourt, 2015).

Similar findings were reported by a multisite study ($N = 558$) conducted by Ganz (2004, as cited in Janz et al., 2007). Moreover, a smaller qualitative study conducted with 15 American

women generated related findings (Sherman et al., 2012). Love and colleagues (2015) also reported comparable findings from her clinical practice, as well as personal experience. She included the following physical problems, namely scarring, cellulitis, radiation-related muscle pain, secondary cancers and cardiac disease, neuropathy, arthralgia, weight gain and bone loss (Love et al., 2015).

These findings indicated similarities of results from both quantitative and qualitative studies. Moreover, the findings revealed the continuous experience of multiple symptoms from primary treatment into survivorship (Janz et al., 2007; Love et al., 2015; Sherman et al., 2012). Yet, a quantitative study ($N = 364$) conducted in Spain, suggested contrasting results (Moro-Valdezate et al., 2013). Fatigue, pain and insomnia, systemic side effects and arm problems decreased during follow-up (Moro-Valdezate et al., 2013). In addition, deterioration in sexual functioning was attributed to menopausal factors and a perceived idea of diminished attractiveness (Moro-Valdezate et al., 2013).

However, a limitation of the study conducted by Moro-Valdezate and colleagues (2013) was the lack of baseline measurements prior to treatment, which was needed for follow-up measurements. Janz and colleagues (2007) also reported discrepancies in existing research results pertaining to variations in physical symptoms and side effects across some combinations of treatment. These discrepancies could be attributed to socio-demographic features, prior health status, education level, financial situation and marital status (Janz et al., 2007).

Existing research demonstrates the significant influence of visual representations of breast cancer treatment, which undoubtedly result in psychological and social challenges (Al-Azri et al., 2014; McCann et al., 2010; Ogden & Lindridge, 2008; Pidlyskyj et al., 2014).

A structured review of psychological aspects: The breast is perceived, at least in the Western world, as the phenomenal symbol of female sexuality (Levin, 2006). At present, and despite transitional demands pertaining to emancipation and feminism, this statement from Levin

(2006) still proves relevant (Carroll, 2016; Stevenson, 2014). Breast cancer is still experienced as a threat to femininity, identity, and self-validation (Al-Azri et al., 2014; Stevenson, 2014).

Keeping this in mind, breast cancer treatment interventions are apprehended as invasive and described as mutilating in nature, therefore, subjecting women (Western, African and Asian) to extreme psychological stress and negative emotional experiences (Fu, Xu, Liu, & Haber, J., 2008; Lindwall & Bergbom, 2009; Love et al., 2015; Whitehead & Hearn, 2015).

Psychological and emotional aspects associated with breast cancer treatment include, psychological distress (depression, anxiety, worry, anger), limited concentration abilities, recurrent nightmares, fear of recurrence, diminished femininity and sexual attractiveness, bodily mutilation and scarring (Ganz, 2008) as well as change in memory, and focus and attention, also known as chemo-brain (Love et al., 2015). Psychological aspects of treatment also include intrusive thoughts (unwanted and recurrent thought), which according to Horowitz (1986 as cited by Dupont, Bower, Stanton, & Ganz, 2014) allude to stressful events such as breast cancer treatment in this context of this study.

Research results from a quantitative study with 558 American women revealed that intrusive thoughts have psychological and physical repercussions (Dupont et al., 2014). Intrusive thoughts are related to psychological distress and a decline in physical functioning (Waldrop et al., 2011; Whitaker, 2008). These intrusive thoughts reflect the woman's existential challenges, her perception of herself and her world, before and after treatment (Dupont et al., 2014; Lindwall & Bergbom, 2009; Whitehead & Hearn, 2015). Existential challenges include a sense of constant threat to self and personal health, fears of injury and death (Sherman et al., 2012) as well as fear of isolation and resentment (Bates et al., 2016).

Fear of death included both the process of dying and, more so, the metaphorical deaths of roles prior to breast cancer (Naidu, 2012; Sherman et al., 2012). The threat to self and personal health refer to women's prior perceptions of themselves as being healthy (absence of illness)

(Sherman et al., 2012), feminine and sexually attractive (Dahl et al., 2010). The threat to self also refers to the loss of privacy, loss of control over intimate bodily processes and promulgation of previously considered intimate parts (Naidu, 2012).

These perceptions are undoubtedly challenged by breast cancer treatment. Breast cancer treatments often result in disfigurement (Henriksen & Hansen, 2009) and therefore altered body image and self-concept (Begovic-Juhant et al., 2012; Dahl et al., 2010; Przezdziecki et al., 2013). According to Przezdziecki and colleagues (2013), body image is a reflection of experiential perception and self-assessment of one's physical appearance. Negative thoughts and feelings related to one's body indicate a disruption of body image and lead to discontentment with one's self (Przezdziecki et al., 2013).

Findings from a literature review regarding factors influencing body image in women with breast cancer revealed the following factors to have a significant impact on body image (Rezaei et al., 2016). These factors include biological factors (age, race, gender, education), sociocultural factors (social status, financial status, cultural status), psychological factors (personal and interpersonal), as well as disease and treatment-related factors (Rezaei et al., 2016). Findings also demonstrated younger women and less educated women to experience significant distress pertaining to body image, physical appearance and sexual functioning (Bloom et al., 2012; Rezaei et al., 2016).

In keeping with the findings from the literature review, results from a study conducted by Begovic-Juhant and colleagues (2012) demonstrated the negative effect of treatment-related surgery (loss of a breast) on body image and self-concept. Results indicated, that for these 70 North American women, "the breast is more than just a body part" therefore the loss of a breast is associated with loss of femininity, loss of sexuality, diminished womanhood, loss of attractiveness, as well as loss of motherhood and nurturance (Begovic-Juhant et al., 2012, p. 447). Following breast surgery, most of these women changed their perceptions regarding their bodies.

Moreover, they experienced pertaining to their previous physical appearance and sense of self (Begovic-Juhant et al., 2012).

Changes in physical appearance, during and after treatment, include deformity, scarring, hair loss, weight gain or loss, burns, and skin pigmentation (Rezaei et al., 2016). These bodily changes are both visceral and visible (Naidu, 2012). Naidu's (2012) narrative research (39 interviews), with 15 South African women, demonstrated 'the body' as the intrinsic and central constituent of 'the self.' Unfortunately, it is unclear whether the 15 women in Naidu's study were representative of the diverse South African population.

An online survey, completed by 279 Australian women, pertaining to body image and breast cancer revealed a correlation between high investment in physical appearance and self-worth, as well as self-compassion (Przedzieck et al., 2013). Changes in physical appearance as a result of breast cancer treatment led to a diminished sense of self-worth, self-criticism, and self-compassion (Kearney & Hicks, 2017; Przedzieck et al., 2013; Waite, Knight, & Lee, 2015). Even though the online survey revealed interesting data, participant bias and limited representation could be considered as possible limitations. Investment in physical appearance, therefore, is a critical aspect of body image (Moreira et al., 2010). Appearance investment also includes the construct, body integrity (Moreira et al., 2010). Body integrity is concerned with the body as a whole, self-esteem, as well as the ability of the body to function correctly (Moreira et al., 2010).

Findings from Moreira and colleagues' (2010) quantitative study, which included 117 Portuguese breast cancer patients, revealed that higher investment in body integrity correlated with higher disruption in social activities and a greater degree of alienation from the self. Even though the study conducted by Moreira and colleagues were limited in respect to participant sampling, the results of this quantitative study were supported by similar findings from Naidu's (2012) qualitative study, which highlighted findings pertaining to the experience of alienation (sense of self-estrangement) and feeling disconnected from one's own body.

Experiences of alienation and disconnectedness to one's body, as well as alterations in body image, often result in individual identity disruption (Naidu, 2012; Price Herndl, 2006; Wolf, 2015). Identity disruption could also be described as biographical disruption, which refers to both positive and negative implications of breast cancer throughout the different phases of this illness trajectory (Koutri & Avdi, 2016; Price Herndl, 2006). Creating a sense of identity, or rather a new sense of identity for an altered body was reported as part of the findings from the narrative study conducted with 15 Greek breast cancer patients (Koutri & Avdi, 2016). These findings pertaining to a new, or rather different and altered, sense of identity were supported by a phenomenological study with 10 Swedish breast cancer patients (Lindwall & Bergbom, 2009).

An important aspect highlighted by Lindwall and Bergbom (2009) was the women's perceptions of the inseparability of body, mind, and soul. Breast cancer treatments, including routine follow-up consultations, undoubtedly threaten this inseparable unit, creating uncertainties pertaining to future health expectations, as well as fear with regard to possible recurrence (Drageset et al., 2015; Koutri & Avdi, 2016; Lindwall & Bergbom, 2009; Sarenmalm et al., 2009).

Research pertaining to fear of recurrence was conducted through an online survey with 3239 American women (Lebel et al., 2013). Results from the survey revealed the constant fear of recurrence, whether in the same body part, or in a different body part or organ, especially in women younger than 34 years of age (Lebel et al., 2013). A qualitative exploration of fear of cancer recurrence amongst Australian and Canadian women ($N = 38$) revealed similar findings (Thewes et al., 2015). In addition, and not surprisingly, the most prevalent fears include, fear of death and, moreover, the process of dying (Sarenmalm et al., 2009; Thewes et al., 2015).

The findings associated with the process of dying, as reported by Sarenmalm and colleagues (2009), included fears pertaining to humiliation, being physically disfigured, becoming physically repugnant, intolerable pain, being a burden and loss of dignity. These findings were generated from 40 interviews with 20 Swiss participants. Lack of information regarding the

sociocultural backgrounds of the participants limits the transferability of the findings. Koutri and Avdi (2016) reported similar findings pertaining to death and dying. Moreover, their study demonstrated the undetermined process of development, which implies underlying uncertainties even in the absence of momental illness (Koutri & Avdi, 2016). From this contradictory statement, I concluded that fear of recurrence seems to be omnipresent in women globally. Findings from a literature review revealed that it is important to note that fear of recurrence is not an irrational fear, rather, it is a multi-faceted experience including fear of further treatment and development and continuation (Ozakinci et al., 2014).

Treatment interventions lead to complications in a woman's connection with her body, her femininity, sexuality and identity (Naidu, 2012). Therefore, treatment interventions and experiences reflect an interruption, separation, and disturbance of the sense of identity (Koutri & Avdi, 2016). Losing a breast is tantamount to numerous losses of salient values including loss of sense of belonging and loss of identity (Begovic-Juhant et al., 2012; Naidu, 2012; Sarenmalm et al., 2009).

2.4.3 Research authentication

Heretofore, Schlebusch (1998) conducted a landmark study, prioritizing South African breast cancer research. This study, as well as other studies, emphasized the psychosocial aspects associated with breast cancer, "psychological stress, adjustment and cross-cultural considerations in South African breast cancer patients" (Schlebusch & Van Oers, 1999, p.30). Despite this, and other research, I conclude that personalized psychosocial support and care with regard to breast cancer diagnosis and treatment experiences are still perceived as secondary in government-supported health care facilities.

An overview of the literature revealed paucity in South African research and, as mentioned previously, no case studies were found (internationally and South Africa) on the subjective experiences of breast cancer diagnosis and treatment. This current study, presented as three case

studies, set out to explore and interpretatively understand the subjective experiences of breast cancer diagnosis and treatment. In view of substantial global research, experiences of breast cancer diagnosis and treatment comprise a considerable list. The gap, however, as highlighted by this literature review, is the paucity of South African research with regards to the particular (unique) subjective experiences of breast cancer diagnosis and treatment of women attending a government-supported health facility. From this review, I also concluded a clear gap in the literature, and more specific South African literature, pertaining to the influence of sociocultural backgrounds and socio-economic factors on the experiences of breast cancer diagnosis. An in-depth discussion of these factors is not warranted in this current study. However, this could be considered for future research.

These three case studies aim to fill the gap currently existing in South African research pertaining to individual experiences of breast cancer diagnosis and treatment. Therefore, primarily, the current qualitative study aimed to give voice to women as being the experts of their own diagnosis and treatment experiences. Using patients' experiences to assess and improve quality health care performances have become one of the focal research points in qualitative research worldwide. As stated by Goodrich and Cornwell (2008): "Patient's stories bring the experience to life, making it accessible to other people...in a way that survey data cannot" (p.7, 17). I sought to report first-hand accounts pertaining to breast cancer diagnosis and treatment experiences, hence my motivation for choosing Interpretative Phenomenological Analysis.

2.5. Meaning-making and coping

Meaning-making and coping are an integral part of phenomenological research, especially Interpretative Phenomenological Analysis. Meaning-making and coping are also fundamental aspects of breast cancer experiences (Martino & Freda, 2016). Coping processes and meaning-making are personal and particular to each individual (Martino & Freda, 2016; Mehrabi et al.,

2015). A diagnosis and treatment of breast cancer may change a woman's perspective on life, her attitude to life and her way of living (Cipora et al., 2017; Drageset et al., 2015; Sarenmalm et al., 2009). Meaning-making in breast cancer happens within a context of a life in peril, thereby forcing women to reappraise their lifeworld and processes of meaning-making and coping (Lindwall & Bergbom, 2009; Sarenmalm et al., 2009). In light of this information, understanding meaning-making and coping are critical to my interpretation of the subjective experiences of women receiving breast cancer diagnosis and treatment.

Existing literature, as discussed in the previous sections, demonstrated that breast cancer (diagnosis and treatment) elicits physical, emotional and psychological, as well as social and spiritual experiences. These experiences are complex and differ between individuals, over time and across situations (Drageset et al., 2015; Kaptein et al., 2015; Kim et al., 2010; Marlow et al., 2003; Preidt, 2009; Waldrop et al., 2011). Moreover, these experiences are affected by circumstantial factors (cancer stage, current treatment, time since diagnosis), managing factors (cancer-defined vs. individual coping) (Drageset et al., 2015; Khalili et al., 2013; Kvillemo & Bränström, 2014), socio-economic factors (education, income) (Cipora et al., 2017; Mehrabi et al., 2015) and sociocultural factors (Martino & Freda 2016).

Individuals' perceptions and interpretations are intricately interwoven with their culture, history, language, and interactions (Khalili et al., 2013; Quest, 2014). Meaning-making and coping practices, within breast cancer diagnosis and treatment experiences, are multi-faceted and complicated individually constructed concepts.

Meaning-making is shaped by the woman's feelings (emotions) and cognitions (beliefs, thoughts, ideas) regarding her experience of breast cancer (Ching, Martinson, & Wong, 2012; Kaptein et al., 2015; Liamputtong & Suwankhong, 2016). Sarenmalm and colleagues (2009) underscore the importance of narration of stories of suffering as part of the healing process. Narratives enable women to reconsider the past in order to make sense of the present and future

(Martino & Freda, 2016; Naidu, 2012; Sarenmalm et al., 2009). Therefore, respectful exploration through narratives, with regard to how breast cancer patients experience, understand and make meaning of their breast cancer, is an essential part of this study. This is in keeping with the principles of qualitative research, and more importantly, the chosen methodology for this study, Interpretative Phenomenological Analysis. The search revealed limited literature on South African breast cancer patients' meaning-making and coping. However, an in-depth exploration and interpretation of meaning-making and coping in breast cancer patients are beyond the scope of this current study, but certainly warrant future research.

2.6 Theoretical frameworks

2.6.1 Introduction and background

The chosen design for this study is phenomenology. Phenomenology should not be organized around preconceived perceptions, expectations and specific frameworks (Creswell 1994 as cited in Anfara & Mertz, 2006; Groenewald, 2004; Tavallaei & Talib, 2010). In view of these arguments, I have reason to present two main theoretical frameworks, as well as one supportive theory, that is relevant to the study and chosen methodology, Interpretative Phenomenological Analysis.

The option selected as a supportive theory for this study is Self-in-Relation theory. The two main theoretical frameworks in which this study is situated are the Biopsychosocial Spiritual model and Constructivism. These three options will be discussed in the next sections. By virtue of the complex nature of these theories, providing a comprehensive analysis is beyond the scope of this present study. Therefore, only theoretical concepts and perspectives, within these theoretical frameworks, pertaining to this study will be considered.

2.6.2 Self-in-relation theory

Self-in-relation theory demonstrates the complexity of women's needs and psychological development within a relational framework (Pilkington, 2007). Sense of identity (the self) is directed, reinforced and maintained in a relational context (Freedberg, 2015). Self-in-relation theory evolved and is currently known as the relational-cultural theory in order to provide for cultural influence in human experiences (Freedberg, 2015). Pilkington (2007) explained the importance of connectivity, especially in the face of adversity, for well-being and preservation of life. Connectivity, more specifically psychological connections with others, often create expectations with regards to sense of identity, self-worth, and competency (Surrey, 1991 as cited by Warwick, 2002). In addition, these expectations often include prioritizing relational issues over independence and self-determination (Warwick, 2002).

In the context of this study, women living with breast cancer may experience inconsistencies between perceived and expected gender role functioning and personal needs (Pilkington, 2007). Therefore, I concluded self-in-relation theory to be significant as part of the theoretical frameworks discussion. An in-depth discussion of Self-in-relation theory is beyond the scope of this study.

2.6.3 Biopsychosocial Spiritual model

The Biopsychosocial model, originally conceptualized by George Engel in the late 1960's (Gibert, 2002), is currently the basis of the World Health Organization's International Classification of Functioning (WHO ICF) (Wade & Halligen, 2017). The intention of developing the Biopsychosocial model was not to replace the Biomedical model, but to offer a complete approach to illness and health (Engel, 1977; Wade & Halligen, 2017). Illness and health are, undeniably, the consequence of interrelationships between biological, psychological and social factors (Deshields & Nanna, 2010; Holland et al., 2015; Wade & Halligen, 2017). Therefore, in the context of the current study pertaining to breast cancer experiences (diagnosis and treatment) the holistic approach of the Biopsychosocial Spiritual model deemed appropriate.

The dynamic, holistic approach of the Biopsychosocial model (Borrell-Carrió, Suchman, & Epstein, 2004) is based on a systems theory (Adler, 2009) with a focus on human quality (humanness), and human experience (Engel, 1997). Systems theory according to von Bertalanffy refer to the ‘whole patient’ and therefore the interrelatedness of biological, physical, psychological, social and cultural phenomena (Holland et al., 2015; Von Bertalanffy, 2013). ‘Whole patient’ refers to these complex relations of a patient in connection to herself, the family, the health care provider and the community (Deshields & Nanna, 2010; Holland et al., 2015; Wade & Halligen, 2017).

In keeping with the ‘whole person’ perspective, a spiritual component was introduced to the Biopsychosocial model, following the findings of a study conducted by Elias and colleagues (2015). The study demonstrated the application of a therapeutic intervention involving “relaxation techniques, mental images and spirituality (RIME)” (Elias et al., 2015, p.2). The findings indicated that RIME enhanced psycho-spiritual transformations, social transformations, as well as interpersonal transformations (Elias et al., 2015). These transformations resulted in the emergence of an increased awareness of meaning and attitudes and ultimately improved quality of life, self-esteem, and hope (Elias et al., 2015).

Carel (2013) reported from own her experience of living with a chronic illness: “The human being is by definition embodied and enworlded, so trying to provide an account of a human being that lacks these elements will result in a deficient account” (p.15). The holistic Biopsychosocial Spiritual model of illness is, therefore, a practical guideline to comprehend the subjective experiences of patients pertaining to diagnosis, treatment and survivorship (Borrell-Carrió et al., 2004; Davis et al., 2014) of breast cancer that would otherwise not be accessible (Engel, 1977). The Biopsychosocial Spiritual model is not without critiques or limitations (Benning, 2015).

Irrespective of acceptance from the WHO this integrative, non-reductionist clinical and theoretical perspective of the Biopsychosocial Spiritual model evoked critiques and limitations. Critiques and limitations refer to unscientific methods (non-analytical understandings), unclear boundaries between the areas (biological, psychological, social and spiritual) and multilateral (pluralistic) viewpoints (Benning, 2015; Henriques, 2011). These, according to Ghaemi (as cited in Henriques, 2011), can lead to insensitivity to the subjective experiences of the patient. In the context of this study, consideration for all domains was applied through continuous reflection of the subjective experiences of these women living with breast cancer.

2.6.4 Constructivism

Constructivist theory emphasizes the individual's understanding, meaning-making and construction of personal realities, including selfhood and personal identity, as well as social and cultural realities, through social interaction (Constantino, 2012; Doolittle & Tech, n.d.; Mahoney & Granvold, 2005). Individuals are recognized as active participants in their own lives, making meaning as they develop (Constantino, 2012; Mahoney & Granvold, 2005). Constructivism and Self-in-Relation-theory emphasize personal psychology (sense of self), social functioning, human adjustment and connectivity (Mahoney & Granvold, 2005).

Within the current study, constructivism highlights the dynamic structure of breast cancer experiences (Mahoney & Granvold, 2005). Constructivist research focuses on participant observation and data generation through interviewing (Constantino, 2012). Interpretative Phenomenological Analysis, the chosen methodology for this present study, is therefore situated within Constructivism. In the context of this study, I attempted to interpretively understand breast cancer from the perspective of the participant through mutual interaction, while being cognizant of my own values and disposition. The research methodology, Interpretative Phenomenological Analysis will be discussed in the following chapter, Chapter 3.

2.7 Concluding remarks

The structured review highlights the perceptions of breast cancer, the physical (biological) and psychological (emotional) aspects, social and spiritual aspects associated with breast cancer, as well as meaning-making and coping responses. In the context of this study, the reason for discussing all the aspects was to give explicit attention to humanness (Engel, 1997) and the breast cancer patient as a ‘whole’ (Holland et al., 2015). This is also in keeping with the holistic approach of the Biopsychosocial Spiritual model as discussed.

The lived experience of an illness such as breast cancer impact on, and changes, people’s perspectives about their bodies and their realities (Brennan, 2014). Living with breast cancer encompasses disruptive events in an effort to preserve some kind of normalcy with regard to overwhelming changes to the body and self (Pirok, 2016). The breast cancer experience is a life-changing process, enforcing radical adjustment throughout the illness trajectory (Sherman et al., 2012). Women with breast cancer need to recognize this illness as being part of their existence and their future realities (Sherman et al., 2012).

Women described their breast cancer experience as an act of traveling through life, simultaneously changing on a physical, emotional, social and spiritual level (Sherman et al., 2012). More than three decades ago, Dr. Martin Abeloff stated: “Therapies have been lengthy, toxic, and disfiguring, adding to the amount of suffering that a patient and family endures. You simply can’t treat cancer without paying attention to the psychological and social aspects of the disease” (Ganz, 2008, p.1, para. 4). With this present study, I wanted to explore, describe, and interpretively understand the lived psychosocial experiences of individual breast cancer patients receiving diagnosis and treatment from a first-person perspective in order to provide customized psychosocial support as part of multidisciplinary health care.

CHAPTER 3

RESEARCH DESIGN AND METHODOLOGY

3.1 Introduction

Chapter 3 describes the research method used for the study. Following the introduction is a review of the research aim and objectives and motivation for the research design. The research setting, participant selection and procedure for participant recruitment will be discussed in the following four sections. Subsequently, I will discuss data collection, data analysis, and trustworthiness, emphasizing Interpretative Phenomenological Analysis (IPA) as the method of choice in the study. This is followed by an overview of the relevant ethical considerations and the conclusion to the chapter.

3.2 Research Aim and Objectives

The primary aim of the study was an in-depth exploration and rigorous interpretation of the lived experiences of breast cancer patients receiving diagnosis and treatment at a public health breast clinic. The objectives of the study were to 1) understand the subjective psychological experience associated with breast cancer diagnosis and treatment, 2) elucidate the subjective physical experience associated with cancer treatment and management, 3) explore specific perceptions and psychosocial needs of breast cancer patients, and 4) identify the meaning-making practices of breast cancer patients.

3.3 Qualitative Research

Qualitative research methods function within an interpretivist model, which recognizes external and internal realities (Carcary, 2009). External realities refer to participants' "physical worlds" and "internal realities refer to realities that are subjective and unique to a participant" (Carcary, 2009, p.12). A particular focus of qualitative research is to understand and describe

subjective realities (Hancock, Ockleford, & Windridge, 2009). The aim of the present study is, therefore, in keeping with the interpretivist goals of qualitative interpretative phenomenological research, which are 1) to rigorously investigate and explore complex human experiences, 2) to empower individuals through sharing their stories, 3) to engage in ‘sense-making’ of intricate and confusing situations and 4) to gain knowledge on how breast cancer patients conceptualize their worlds (Babchuk & Badiiee, 2010; Carcary, 2009) from their intersubjective frame of mind (Allen, Eatough, & Ungar, 2016). I chose to do qualitative research on the subjective experiences of breast cancer in order to discover and learn how breast cancer patients think and make meaning of their experiences.

3.4 Motivation for Interpretative Phenomenological Approach

My motivation for choosing IPA is the limited availability of information on subjective diagnosis-related and treatment-related experiences of South African women attending a public health breast cancer clinic. I chose IPA instead of Thematic Analysis because I wanted to emphasize *how* women with breast cancer understand and make sense of their illness, the significance of breast cancer as it pertains to them as individuals and *how* they express their feelings in their own terms (Smith et al., 2009). My aim was not to identify and report on patterned responses (themes) across the data corpus, rather my aim was to elicit a thick description that allowed participants to share their idiographic interpretation of their breast cancer experience and my interpretation of their reports.

3.5 Research setting

The study was conducted at the Breast Clinic at Tygerberg Hospital, in the Western Cape, South Africa. The Breast Clinic provides health care to referring patients residing in Cape Town, neighboring suburbs, and towns. Professor Justus Apffelstaedt (personal communication, October

30, 2015), Head of the Breast Clinic at Tygerberg Hospital and Associate Professor of Surgery at the University of Stellenbosch, reported that, on average, 50 women are newly diagnosed with breast cancer monthly. Seventy percent of these patients fall in the very low-income group, earning between R500 and R1200 a month, or rely on government grants. Transportation expense to Tygerberg Hospital could amount to R150 and more per single visit (Apffelstaedt, 2016).

During consultation with an attending clinician, the patients receive a diagnosis and information on treatment interventions and management options. Diagnosis and stage of breast cancer are confirmed by physical examination, possible mammogram and/or fine needle aspiration. Diagnosis and staging are succeeded by treatment interventions, e.g., partial or full mastectomy, lumpectomy, chemotherapy, radiation therapy, and endocrine therapy. Treatment could involve a combination of the above-mentioned interventions. Currently, no additional psychosocial support by health care providers, e.g., psychologists, are available as part of routine care at the Breast Clinic at Tygerberg Hospital.

3.6 Participants selection and recruitment procedures

Selection: The women included in this study are outpatients attending the breast clinic at Tygerberg hospital. Identification and recruitment of participants for this study were by means of purposive sampling, a method of sampling typically used in IPA studies (Bless, Higson-Smith & Kagee, 2006). Participant selection is purposively based on shared characteristics that would allow for detailed investigation of a phenomenon (Bless et al., 2006; Shinebourne, 2011). Purposive sampling is a method used to intently seek a designated sample for which the research question would be applicable (Smith & Eatough, 2007).

The research question for this Interpretative Phenomenology study warrants an in-depth exploration of breast cancer experiences. Interpretative Phenomenological Analysis studies suggest fewer participants and quality of data (Shinebourne, 2011). The quality of data was,

therefore, an important determinant in deciding on sample size for the current study. Quality of data included characteristics such as appropriate time-length for an interview, thoughtful responses and interest in the study from willing participants (McKay, 2014). According to Fink and Beck (2015), good quality health information should include relevance to the topic, comprehensiveness, granularity (level of detail), currency and timeliness as well as proper definitions. Therefore, in keeping with the principles of IPA, the participants involved in this study were chosen on the basis of their ‘lived experience’ and first-person accounts of breast cancer. Inclusion criteria for participant recruitment included voluntary participants, 18 years and older, receiving a diagnosis and/or treatment at the Breast Clinic at Tygerberg Hospital. Participants had to be relatively fluent in English or Afrikaans, and proper understanding of English or Afrikaans were required. Participants with any known impending mortal illness, disease or disorder were excluded.

Recruitment: The current study is part of a larger ongoing study. Participant recruitment was achieved by two methods. Participants were recruited by means of a personal request, or of their own accord. A personal request included an introduction of myself and an explanation of the study at the time of the patient’s follow-up visit to the breast clinic. This became the primary method of recruitment. Patients received brochures at the breast clinic and were informed to contact the investigators of the larger study (my supervisors), should they wish to partake in the study. One woman contacted my co-supervisor, electronically, of her own accord and was referred to me. Upon visiting the breast clinic over a period of eight weeks, I recruited nine patients who voluntary showed interest and willingness to partake in the study. In total, 10 participants were recruited into my study of which three participants’ interviews were selected for the case study approach.

I explained the following to each participant prior to conducting the interviews 1) the aim of the research study pertaining to the psychosocial experiences associated with breast cancer, 2) the

anticipated length of the interview, being between 30 and 60 minutes, 3) voluntary participation and that the participant was allowed to stop the interview or leave the study at any time. The opportunity was given to the participant to ask questions and clarify any misconceptions. Written permission was requested for an audio recording of the interview for transcription purposes. I also explained and ensured anonymity and confidentiality regarding medical and personal information. After agreeing to partake the participants were asked to read and sign the patient leaflet and informed consent form (see Appendix A).

Participants expressed interest in taking part in the study and some expressed gratitude for the opportunity to tell their story. Participants were allowed to take a copy of the patient leaflet, which contains health care referral information for future reference. Participants were not initially informed of the 50 rand voucher they would receive on completion of the interview. Additional information on the study was available at the Breast Clinic by means of wall posters and brochures.

3.7 Participants' demographic information

Participants' demographic information was gathered by means of their hospital patient folder and during the course of the interview. Demographic information includes the following 1) participant's code, 2) participant's pseudonym, 3) participant's age, 4) year of diagnosis, 5) stage of breast cancer with diagnosis, 6) co-morbidity with other forms of cancer, 7), family history of cancer, 8) chemotherapy received as treatment, 9) radiation received as treatment, 10) unilateral or bilateral mastectomy as surgical intervention and 11) lumpectomy as surgical intervention. After written consent was obtained from each participant, verbal permission was given by the hospital personnel to access participants' folders in order to collect demographic information. See Appendix B for a detailed account of the participants' demographic information.

3.8 Data collection

In keeping with the goals of qualitative research, “participants are considered experts of their own experiences who can offer researchers an understanding of their thoughts, commitments and feelings through telling their own stories, in their own words, and in as much detail as possible” (Reid, Flowers, & Larkin, 2005, p. 20). Data collection for this study was through in-depth, semi-structured interviews. According to Pietkiewicz and Smith (2014), semi-structured interviews allowed for adaptability within the interview, this gave me, as the researcher, sufficient opportunity to reflect and investigate actual and unexpected issues that might arise.

After receiving sufficient training in interviewing skills from both my supervisors, as well as informed written consent, I conducted every interview myself, using a semi-structured interview schedule as guidance. See Appendix C for detail. The semi-structured interviews were conducted in a private consultation room at the Breast Clinic. Participants indicated distress at the possibility of losing their positions in the queue after waiting for two to four hours in order to see the doctor. Distress could impact on the quality of the interview, and I did not want to compromise on the quality of information. I therefore reassured the participant that all relevant staff had been notified of the interview, both verbally and in writing (A4 size sheet of paper with patient’s name and number was put between patient folders).

Interview questions were consistent and I took great care not to ask double-barreled and leading questions intentionally, or use unconventional medical terminology (Harrell & Bradley, 2009). Ten interviews were conducted of which nine interviews were conducted in Afrikaans and one interview was conducted in English. Nine participants were interviewed at the breast clinic on the day of their follow-up consultation. I allowed time to reflect on each interview in order to explore possible improvement of my interviewing skills. The in-depth semi-structured interviews were conducted during a follow-visit in the privacy of an interview room situated in the breast clinic at Tygerberg hospital. One participant, Lily, was interviewed at her home.

I facilitated the semi-structured interview whilst guiding the participant by using applicable and approved open-ended questions. I allowed each participant the appropriate time and opportunity to share her experiences (Smith & Eatough, 2007). My aim was to attend actively to the participant's perspective of her experiences by presenting an open approach. Dahlberg et al., (2001, as cited in Finlay, 2008) define this open approach as follows, "Openness is the mark of a true willingness to listen, see, and understand. It involves respect, and certain humility toward the phenomenon, as well as sensitivity and flexibility" (p. 5). I therefore also allowed comfortable moments of silence during the semi-structured interview, allowing the participant and myself to reflect on matters of importance (Pietkiewicz & Smith, 2014; Vagle, 2016).

The semi-structured interview schedule included three sections of research questions (see Appendix C). Section A pertained to experiences with diagnosis and perceived social support during and after receiving a diagnosis. Section B was concerned with experiences with treatment and perceived social support during and after receiving treatment. Section C covered psychological and emotional experiences associated with body image, personal relationships, quality of life, overall wellbeing and meaningfulness. The research questions elicited thick description through rich narrative on how patients experienced their diagnosis and treatment of breast cancer.

I conducted 10 individual interviews which each lasted between 15 minutes and 46 minutes. According to Bless et al. (2006), the interviewer has a responsibility towards the interviewee to maintain the quality of the personal contact whilst being flexible and objective during the interview and processing of information. I strove to maintain flexibility and objectivity by showing kindness and giving each participant the necessary respect, time and opportunity to talk about their experiences. Objectivity referred to a constant internal awareness of my own perceptions and ideas. Flexibility (adaptability) within the interview process elicited unanticipated narratives, which lead to valuable descriptions and interpretations.

The interviewer's responsibility to maintain quality during the interview procedure includes using comprehensible language when asking questions to avert influencing participant responses (Harrell & Bradley, 2009). I aimed to maintain quality by asking open-ended questions and allowing the participant to answer as she saw fit.

Upon conclusion of the interview, I thanked participants for their participation and informed them of their rights. These rights included withdrawal from the study at any given time, refusal to answer as well as only giving information that they felt comfortable with. None of the participants withdrew from the interview or the study. I monitored participants for any signs of emotional distress during the course of the interview (Pietkiewicz & Smith, 2014). Thickness of description, fulfillment of aim and objectives of the study as well as time constraints guided conclusion of interviews.

3.9 Data Management

The interviews were audio recorded and transcribed. I marked each audio recording and transcription with a participant number and the participants' initials. A pseudonym was chosen for discussion of results. Pseudonyms conserve anonymity and provide a sense of individuality to participants. I used field notes to record additional data (Groenewald, 2004), which included medical information pertaining to the year of diagnosis, cancer stage at diagnosis and personal communication before audio recording. Field notes and raw data were stored electronically on both supervisors' and my own private computer. All information and transcriptions were password protected and treated as confidential and anonymous.

I personally transcribed four interviews. An external transcription company was appointed to transcribe six interviews. I listened to each audio recording as many times as was needed, simultaneously reading and correcting the transcriptions done by the transcription company and myself. Audio-recorded data was transcribed verbatim, often containing many grammatical errors

and cultural-influenced pronunciations of certain words and phrases.

The transcription process gave me the opportunity to engage with the individual interviews on a deeper level, as well as familiarizing myself with the information whilst recognizing significant non-verbal communication. During the transcription process, I created two columns on the right side of the transcript text for comments and summaries. The first column referred to my initial thoughts on the text within the transcript. The second column referred to psychological concepts and unique characteristics found within the transcript.

However, on account of the volume of data generated, I decided to manage the selected transcriptions, according to IPA step-by-step guidelines as suggested by Smith and colleagues (2009), in a separate document. In this document, I reported in-depth descriptive comments, initial interpretations, descriptive keywords, linguistic comments, conceptual comments and an initial interpretative summary. Interpretative Phenomenological Analysis provided flexible data management guidelines that allowed me to focus simultaneously on similarities and differences in experiences (Pietkiewicz & Smith, 2014). Interpretative Phenomenological Analysis also gave me the opportunity to explore differences within similar experiences. Following is a detailed discussion of IPA.

3.10 Data analysis: Interpretative Phenomenological Analysis (IPA)

3.10.1 Introduction

The essence of IPA is the analytical exploration of how individuals make sense of their experiences (Pietkiewicz & Smith, 2014; Shinebourne, 2011; Smith, Flowers, & Larkin 2009). This study made use of IPA to investigate and interpret the intersubjective experiences of breast cancer patients receiving diagnosis and treatment. The choice of case study design was guided by practical and sensible considerations for participants of which most live in small towns as far as 400 to 500 km from the hospital. Interpretative Phenomenological Analysis case study research

can be done with a relatively small group of participants, focusing on individual differences rather than individual changes over time (Salkind, 2010).

Interpretative Phenomenological Analysis principles provided for a flexible and attainable approach to research with the intention of giving an in-depth narration and interpretation that benefit individuals (Hendry, McLafferty, Pringle, & Drummond, 2011). Interpretative Phenomenological Analysis is a dynamic process wherein the researcher (myself) is the active interpreter of the interpretations of the participants (Smith & Osborn, 2008).

Interpretative Phenomenological Analysis, therefore, provided me with flexible guidelines, allowing me to focus on similarities and differences in experiences, (Pietkiewicz & Smith, 2014; Smith et al., 2009) simultaneously keeping in mind the unique contextual, social, historical and cultural perspectives of each individual participant.

3.10.2 Theoretical orientations of IPA

Phenomenology is rooted in the philosophical ideas of Edmund Husserl (1859-1938), who emphasized the examination of consciousness, perception, and awareness (Smith et al., 2009). Phenomenology in the current study refers to the unique conscious experiences of 10 women living with breast cancer. Interpretative Phenomenological Analysis was used for three interviews. Even though breast cancer is the common denominator, each woman described and interpreted this living experience from their own unique perspective, as cultured within the circumstances of their real world.

Heidegger (1962) added to Husserl's concept, by advancing phenomenology from his own perspectives of always being a 'person-in-context' and his idea of inter-subjectivity (Smith et al., 2009). 'Person-in-context' and inter-subjectivity refer to being conscious of the "things, people, relationships and language" of our world as a "significant world" (Smith et al., 2009, p. 16). Consciousness is in keeping with Heidegger's idea of 'Dasein'. Dasein is defined as the way human beings experience existence and, specifically, each moment in life (Wheeler, 2016).

Heidegger also explained the emergence of hermeneutics and the philosophy of existence (Pietkiewicz & Smith, 2014). Hermeneutics is the comprehension of the text and human behavior, which include language, speech patterns, social groupings and ritualistic performances (Gavin, 2008). According to Smith, Flowers, and Larkin (2009), “Without the phenomenology, there would be nothing to interpret; without the hermeneutics, the phenomenon would not be seen” (p. 37).

Hermeneutics, as applied in this study, refers to the interpretation of the text as supplied by the breast cancer patients as well as an attempt to understand the significance of their symbolic and actual expressions (Gjesdal, 2015). According to Pietkiewicz and Smith (2012), “hermeneutics refers to an interpretive activity by the researcher, attempting to understand what it is like to stand in the shoes of the subject” (p. 362). This interpretive action refers to the intense participation of the researcher by means of preconceived ideas and is also called ‘double hermeneutics’ (Shinebourne, 2011).

Merleau-Ponty agreed with these interpretative characteristics but his emphasis was on our *embodied* relationship to our world, wherein our body is central in our connection to the world (Smith et al., 2009). Sartre (1956/1943) believed that the process of development of human beings is an ongoing process in which people are self-conscious, and actively seek meaning in their experiences (Smith et al., 2009). Self-consciousness includes, according to Sartre: “the concern with what we will be, rather than what we are” (Smith et al., 2009. p. 19).

Idiographic research is concerned with a sense of the ‘particular’ and allows in-depth analysis and investigation of individual aspects within their distinctive circumstances (Pietkiewicz & Smith, 2014; Smith et al., 2009). In choosing IPA, I was able to do an idiographic exploration of these different perspectives through in-depth analysis of collected psychological, emotional, social and physical information.

3.10.3 IPA and the current study

As outlined in the proposal for the current study I intended to recruit 10 participants and analyze all interviews using IPA. However, not all the interviews elicited a thick description suitable to IPA. Some interviews were too brief and participants did not reflect much on their experience. On advisement from my co-supervisor, Dr. Roomaney, I chose only to analyze three of my interviews. This is in keeping with Smith and colleagues (2009) who suggest a sample size of three ($n = 3$) for an IPA study at Masters level.

The selection process of three interviews was conducted in collaboration with my co-supervisor. Upon careful reflection and thorough exploration of each of the 10 interviews, we subsequently selected three interviews. The three selected interviews adhered to the following criteria, 1) good quality of data according to characteristics discussed in section 3.6 and 2) the level of rapport and quality of personal contact that I, as the researcher, established with the participant.

Phenomenology allows me to investigate these lived experiences and the complexity of breast cancer. Interpretative Phenomenological Analysis “retain the voice” of the individual’s personal and intimate account and perception of the experience or phenomenon (Larkin, Watts, & Clifton, 2008, Pietkiewicz & Smith, 2012, p. 368) as the individual is trying to make sense of *her* reality (Creswell, 2016; Smith & Osborne, 2008). Interpretative Phenomenological A is therefore applicable in the current study because it allows for the exploration of the visible and the visceral in both participant and researcher. Smith & Eatough (2007) delivered the following statement: “IPA has a humanistically informed holistic model of the person but is still oriented to research within academia and within psychology as a discipline” (p. 5).

3.10.4 Analysis

My IPA comprised the iterative process of advancing from the specific to the shared and back, as well as moving from a descriptive stance to an interpretative perspective, and back (Smith

& Eatough, 2007; Smith et al., 2009). I adhered to the following flexible guidelines as proposed by Smith and colleagues (2009) to analyze each individual transcript.

Firstly, I acquainted myself with the data by listening and re-listening to the recorded data and reading the transcribed data a number of times. I immersed myself in the data by highlighting and commenting on participant responses, which I thought to be important.

Initial noting, step two, included exploratory comments, summaries, paraphrasing, connections and initial explanations. I reported and highlighted non-verbal behavior as well as descriptive comments, the specific use of language, e.g., contradictions, echoes, and elaborations. I also noted the use of pronouns, pauses, repetitions, and metaphors, before moving to more conceptual comments. Careful consideration was applied during interpretation of linguistic descriptions of experiences, e.g., the use of words such as ‘I’ versus ‘they’, (Smith et al., 2013 as cited in Callary, Rathwell, & Young, 2015; Smith & Eatough, 2007), ‘it’ instead of ‘cancer’.

Consistent with the two-stage interpretation process of IPA, I first and foremost focused on the concreteness of the participant’s experiences (Wertz, 2005 as cited by Finlay, 2008) and how she understood, explained and made sense of her world in her own terms (Pietkiewicz & Smith, 2014; Smith et al., 2009). Concreteness, as explained by Finlay (2008), refers to the particulars of the lived experiences rather than the participant’s intellectual interpretations of the phenomenon. The second part of the two-stage interpretation, also called double hermeneutics, comprised my interpretations of the participants’ interpretations of breast cancer.

Interpreting the interpretations of the participants, I applied Schleiermacher’s holistic view of the interpretative process (Smith et al., 2009). Schleiermacher described interpretation as both grammatical and psychological (Smith et al., 2009). Grammatical interpretation refers to accurate and objective textual meaning, and psychological interpretation is concerned with the individuality of the author (Smith et al., 2009). The brief expressions (catchphrases) as stated in the conceptual headings

in the findings sections of the three case studies reflected my psychological interpretation of the participants' breast cancer experiences, as well as my individuality.

In the next step, step 3, I transformed the initial notes and comments into comprehensive phrases. These phrases described the important characteristics of the transcribed data, which allowed for the development of psychological concepts (Pietkiewicz & Smith, 2014).

Psychological conceptualization in IPA refers to the generation of comprehensive phrases, which is similar to transforming initial notes into emergent themes (Pietkiewicz & Smith, 2014).

In IPA it is essential to have a theoretical connection between a psychological concept, the researcher's primary response/interpretation and the participant's actual words. Following the development of psychological concepts is step 4. I focused on the in-depth exploration of connections between psychological concepts. For the purpose of this study, I am using the term, psychological concepts to dispel any confusion between this being an IPA study and not a thematic analysis. Associated psychological concepts were classified under one emergent overarching superordinate concept.

The rigorous, in-depth analysis consequently led to the emergence of a single comprehensive psychological concept of what it means to live with breast cancer namely, 'Loss of Sense of Personal Identity.' Kubie (2014) describes Personal Identity in terms of six components namely: "1) Autobiographical identity, 2) Body identity, 3) Sense of Agency, 4) Social identity, 5) Beliefs and 6) Conscious identity" (para. 2-6). These components were integrated into the objectives of the study, which refer to the physical experience, psychological and emotional experience and psychosocial needs and experiences.

For the purpose of this case study research each of the six components will be explored and described in relation to the aim and objectives of the study whilst focusing on the three most important aspects pertaining to the research question. The three aspects are breast cancer diagnosis, breast cancer treatment interventions and meaning-making practices.

Superordinate psychological concepts from one transcript could be used as analyzing guidelines for other transcripts. In this study, I did not use the analyses of one transcript as a guideline for the rest of the transcripts. I treated every transcript with the same amount of anticipation, focusing on the particular detail of that specific participant's narrative. My goal was to 'give voice' to each participant's unique experiences throughout the transcription process. During the interpretation process, I felt ethically bound to honor the process of transformation as defined by Willig (2013) as "what presents itself is looked at in a new light, from a different angle, through a different lens" (p. 45). Once the careful and rigorous analysis of all transcribed data was accomplished, one overarching superordinate psychological concept (PC) emerged by means of subsumption. Subsumption is the process through which one emergent concept receives superordinate status (Smith et al., 2009). I identified and explored three subordinate psychological concepts, which were in keeping with the research question and objectives of the study.

In the discussion I explored and grouped the psychological concepts according to similarities found (Pietkiewicz & Smith, 2014; Smith & Eatough, 2007; Smith & Osborn, 2008; Sooben, 2008; Waite, Knight, & Lee, 2015) as well as highlighting the differences within similar experiences across the three case studies. I looked at similarities in experiences and, moreover, I emphasized the idiographic particularities of participants' experiences. This process of emphasizing particularities, as well as similarities and differences across the three studies is a step closer to understanding our shared humanity.

Shared humanity, according to Warnock, is more than a shared human situation or shared experiences, it impacts on our perspectives of what being human personifies (Smith et al., 2009). Therefore, my aim with the study was consistent with the aim of IPA, which was not to anticipate general conceptions about breast cancer experiences but rather to identify particular idiographic concepts and aspects of our shared humanity, and only following a meticulous analysis of each individual case (Smith et al., 2009).

3.11 Ethical clearance

This study had been approved by the Health Research Ethics Committee at Stellenbosch University (see Appendix D). Ethics Reference #: N15/08/077. Permission to conduct the study had been granted by the Western Cape Department of Health (see Appendix E). This study was conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

3.12 Ethical considerations

Adherence to ethical principles ensured ethical conduct throughout the entire research process. The hospital personnel and nursing staff were respectfully thanked and asked regarding the availability of consultation rooms, permission to use the available consulting room and suitability of time to conduct interviews. Great care was taken not to intrude on the daily functioning of the breast clinic, e.g., ensuring that the participant's consultation with the clinician was not delayed by her partaking in this study. Therefore the nursing staff was kept informed regarding which participant was being interviewed.

Privacy of participants was protected and prioritized. All information, audio recordings, and transcriptions are being kept confidential and safe. The anonymity of participants is respected and ensured by removing all information that might lead to identification. Pseudonyms were used for participants, their family, friends, and places of interest as mentioned during the interviews.

Participant safety, comfort, and well-being were of utmost importance during the entire research process. The participants received referral information during the informed consent process, were they distressed at any given time (see Appendix A).

Informed consent encompasses the complete understanding of all risks and benefits pertaining to research and respects a potential participant's discretionary decision (Grady et al.,

2017). Informed consent is one procedure used to establish ethical practice (Denzin & Giardina 2016; Morrell, Epstein, & Moletsane, 2012). All eligible participants were informed of the purpose of this study by either the attending clinician, nursing staff and/or myself. The participants had to willingly sign an informed consent form giving permission to participate in the study and giving permission for audio recordings of interviews (see Appendix A).

3.13. Rigor and Trustworthiness: Quality assessment in qualitative research

Exploring the intricate perspectives of individuals with the intent of interpretation of their meaning-making could be seen as scientifically problematic in assessing the rigor of the qualitative data. According to Billups (2014): “The quest for rigor in any qualitative study ultimately resides with the quality of the researcher’s purpose and practice, and the verity of the unique depth and breadth of each participant’s ‘lived experience.’ ” (p. 4).

Quantitative criteria for rigor are the positivist terms of validity, reliability, and generalizability (Loh, 2013). In their classic work, *Natural Inquiry*, Lincoln and Guba (1985) provided the revolutionary term, *trustworthiness*, as the qualitative replacement for the positivist terminology of validity, reliability, and generalizability.

Trustworthiness refers to the morality, integrity, and ethics of data collected from participants (Macnee & McGabe, 2008). Trustworthiness criteria include credibility, transferability, dependability, and confirmability. I adhered to trustworthiness through the implementation of these criteria whilst situating the participants’ experiences as most important. (Lietz, Langer, & Furman, 2006; Morrow, 2005). I established credibility for this study by immersing myself in the collected data, and therefore in the participant's world. I have also made a calculated and conscious attempt to be aware of my own assumptions, attributes, and preferences. By means of a process termed ‘bracketing’, I strove to separate my own experiences and

perspectives from unduly influencing the research (Callary et al., 2015; Chan, Fung, & Chien, 2013).

Transferability refers to the degree of application of findings to additional similar situations (Anney, 2014; Houghton, Casey, Shaw, & Murphy, 2013; Lincoln & Guba, 1985). Morrow & Smith (2000) stated that transferability in qualitative research corresponds to generalizability, also known as external validity in quantitative research. In light of the idiographic nature of IPA, as well as the individualistic methodological approach used, I did not adhere to transferability as described above. I did, however, respect and comply with theoretical transferability or generalizability of collected data through a thick description of commonalities (Pringle, Drummond, McLafferty, & Hendry, 2011) allowing fellow researchers to compare evidence with current professional and experiential philosophies (Smith et al., 2009). Commonalities in participants' narratives and descriptive research accounts might lead to insightful awareness and understanding which could be applied to a wider audience (Reid, Flowers, & Larkin, 2005).

Dependability in qualitative research is similar to reliability in quantitative research (Anney, 2014; Lincoln & Guba, 1985). During the interview process, I referred my interpretations of experiences to the participant in order to clarify any misconceptions that might occur in an effort to adhere to the dependability of the findings. I also discussed my interpretations of participants' experiences with my supervisors.

Confirmability in qualitative research is parallel to objectivity in quantitative research (Morrow & Smith, 2000). Lincoln and Guba (1985) define confirmability as the researcher's degree of impartiality towards the findings of a study, as well as the researcher's responsibility to ensure that the findings reflect the participants' real world. Confirmability in this study was achieved by means of an audit trail wherein visible evidence was provided pertaining to the research process and findings (Anney, 2014). Trustworthiness of this research was further

enhanced by mutual commitment, and engagement with the data, from my supervisor and co-supervisor.

3.14 The research audit trail

The research audit trail is a recommended strategy for evaluating the trustworthiness of qualitative data and quality in qualitative methods (Carcary, 2009). I established an audit trail through continuous record keeping of decisions regarding data collection and data analysis (Macnee & McGabe, 2008). Carcary (2009) described research audit trails as either intellectual or physical in character. In my opinion, a research trail consists of both intellectual and physical properties. Intellectual properties refer to my (as the researcher) reflexivity and physical properties refer to the documentation of all stages of the research study (Carcary, 2009). I confirm that trustworthiness in this study was maintained by means of a proper research audit trail. The research audit trail for my study includes proper and thorough documentation by means of interview transcripts, field notes, a personal journal and data analysis substantiation. Effective and comprehensive audit trails are maintained through the researcher's reflective journaling of all aspects and stages related to the study (Gadamer, 1976; Hancock et al., 2009). Reflexivity will be discussed in the following section.

3.15 Reflexivity

Researcher reflexivity: Reflexive journaling consists of two parts namely, researcher (personal) reflexivity and methodological reflexivity (Lincoln & Guba, 1985). According to Morrow and Smith (2005), the researcher is challenged to keep an open mind whilst representing the experiences of the participants. I acknowledged the participants as experts of their own experiences. Moreover, I acknowledged my personal struggle with partisanship. Reflections of my personal experiences were documented in a journal throughout the course of this study, which helped me to clarify impartiality and focus on the participant's reality. Researcher reflexivity is an

inextricable aspect of trustworthiness; therefore it is imperative for conducting proficient qualitative research (Lincoln & Guba, 1985).

I was cognizant of the fact that my disposition as a researcher might have informed numerous aspects of this research study. I am a white, middle age, middle-class, Afrikaans-speaking woman living in Stellenbosch, South Africa. The participants were predominantly low-income Afrikaans-speaking women from different ethnic groups. Although never mentioned per se, (perceived) class and racial differences could have influenced the researcher-participant relationship. The participants could have altered their responses based on their assumptions. Assumptions, in the context of this study, could have included the participants' perspectives on researcher authority, as well as my ability (or lack thereof) to fully comprehend their experiences.

My personal history with breast cancer, including my range of work experiences as a registered nursing sister, shaped my values and beliefs. Information pertaining to my personal history with breast cancer was selectively shared with participants to enhance rapport building. My personal history includes sharing breast cancer experiences with my mother, my mother-in-law as well as caring (home nursing) for my very good friend (and her family) during the last four months of being terminally ill. These experiences undoubtedly changed my perspective on breast cancer and life. These experiences also provided opportunities for personal growth and enhanced empathetic perceptions.

My background as a nursing sister, working in both psychiatry and oncology, prepared me in numerous ways (recognized and concealed) for this research journey. I was constantly aware of the individual (woman) as a person not only as a patient or participant. During the interview, I deliberately made an effort to see (and listen) beyond the breast cancer patient-label.

I concluded that these efforts lead to enhanced rapport, which in turn resulted in generating rich descriptive data. These experiences are intricately woven into my being; I cannot ignore, neither escape, my past. Bearing this in mind and the personal bias that I took with me into the

dialogical relationship, I made a calculated decision to use my preconceptions and motivations, as well as my subjective investment in breast cancer, positively. This approach helped me to contextualize the research and refine the questions asked, recognizing the participants as experts of their experiences.

Methodological reflexivity: Methodological reflexivity is “inevitably theory bound...it is the key competence for any empirical research, quantitative or qualitative. The basic methodological requirement for both groups of methods is sense adequacy” (Eberle, 2016, p.6). In keeping with the principles of IPA, sense adequacy refers to proficient ways of making sense in a pre-interpreted world (Eberle, 2016). In view of this, I was mindful of my partial access to the pre-interpreted world (many possible meanings and perceptions) of women (the study participants) living with breast cancer.

With regard to sense adequacy and quality of findings, I considered the interpretation of these meaning and perceptions a personal challenge. According to Caetano (2015), the time interval between experiencing a specific moment, e.g., receiving a breast cancer diagnosis, and producing a narrative pertaining to that specific experience (moment), could influence the quality of the findings. Narratives are subject to past and present memories, experiences, social circumstances and emotional states.

Therefore, over time, narratives often reflect possible reconstructions of meanings and versions (Caetano, 2015). Reconstructions of meaning influence sense adequacy, which in turn affects the quality of findings (Caetano, 2015; Eberle, 2016). In the context of the current study, even though the time interval between receiving diagnosis and treatment and talking about the experiences were years, the women gave rich, in-depth cognitive and behavioral descriptions of their experiences.

Furthermore, an important aspect to consider in the methodological reflexivity of this Interpretative Phenomenological Analysis was the interview. Each participant took part in one semi-structured interview. I personally value face-to-face interviews because of the discrete benefit and privilege it bestows upon the researcher to establish rapport with potential participants. Conducting the interviews often left me with feelings of hopelessness, ineptness, and guilt. Personal feelings of guilt arose because of my powerlessness to alleviate the immediate desperation of these women. I felt constrained within historical, cultural and medical contexts.

I also felt guilty because my privileged heritage relieves me from having to sit in the queue for hours to be seen by a clinician. Often I felt torn between my personal quest to help versus professionalism and ethics, which allowed me to show compassion but prevented me from acting humane. These feelings and emotions were based on my own personal bias and value system. Conducting the interviews also left me in awe of these women who refuse to be incapacitated by their illness.

The women's acceptance of their fate and their will to live a meaningful life in order to provide for their families evoked adoration. I was humbled and empowered by these strong and spiritual women who, in the face of adversity (chronic illness, poverty, violence) still remained faithful and happy to be alive.

I always left the breast clinic with an emotionally cluttered mind. Days after conducting the interviews, I would still experience wrestling emotions, thoughts and feelings. I had an inherent need to talk about my experiences. This experience left me however with a question and concern. Firstly, regarding the technical and interactive competencies of novice data collectors irrespective of age. Secondly, regarding the psychological impact of data collection on data collectors, all of which ultimately influence the research findings.

3.16 Conclusion

The present chapter provided a detailed description of the research methodology, IPA, chosen for this particular study pertaining to the subjective psychosocial experiences of breast cancer patients receiving diagnosis and treatment. Interpretative Phenomenological Analysis as used in this study allowed for attentive descriptions of experiences and words used by participants. Equally important, IPA enabled me to locate the participants' perceptions and involvement within the context of their significant realities (Larkin, Watts & Clifton, 2008; Smith et al., 2009).

According to Smith and Eatough (2007), an IPA study shows mastery when interpretative possibilities could be extended to a wider audience. Chapters 4 to 6 are presentations of the findings from the IPA studies of Lily, Mina, and Ester respectively. Chapter 7 comprises the discussion of the findings.

CHAPTER 4

ANALYSIS AND FINDINGS:

LILY

4.1 Introduction

The primary aim of this case study is the in-depth exploration and interpretation of Lily's subjective experiences of breast cancer. Chapter 4 presents my interpretation of the findings generated from Lily's descriptions.

I am first presenting Lily in context, which is a description of Lily's background, providing the reader a brief look into the 'lifeworld' of Lily (Willig, 2013). Lifeworld is a term devised by Husserl (1937, as cited by Finlay, 2008) as 'Lebenswelt' and refers to a perception of ourselves as individuals, our bodies, our social and perceptual experiences of the world around us. Descriptions (verbatim excerpts) from Lily provide insight into context-specific settings (Gavin, 2008), which include her economic environment, social environment and individual characteristics (Litaker & Tomolo, 2007). Emphasizing the significance of context is consistent with the values of qualitative research as explained in chapter three (Burgess et al., 2005 as cited in Sheppard, Harper, Davis, Hirpa & Makambi, 2014).

I thought it important to present the idiographic commitment to the findings of Lily's case as a separate section. Interpretative phenomenological analysis fundamentally relies on an idiographic approach (Smith & Osborn, 2008). In the next section, I discuss the findings, which consist of four concepts, namely Lily's perception of breast cancer, her experiences of breast cancer diagnosis and treatment, as well as Lily's meaning-making and coping.

4.2 Lily in context

Lily is a 50-year old, educated Afrikaans-speaking woman who was diagnosed with stage IV breast cancer in 2011. She lives in a two-bedroom house with her second husband and

her daughter from a previous marriage. She currently works as a bookkeeper. During the course of our interview, Lily often mentioned her occupation and the negative impact breast cancer had on her work.

Lily received a study information leaflet from the breast clinic at Tygerberg Hospital. She contacted Dr. Roomaney in May 2016, indicating her willingness to partake. Subsequently, I made contact with Lily to inform her about the study, and we arranged to meet at her home for the interview.

The single semi-structured interview lasted 46 minutes. During the interview, Lily came across as being confident and in control. I surmised that being interviewed in a familiar environment probably made Lily feel safe and secure, reinforcing her personal identity, sense of agency and dignity.

In my opinion, Lily's decisions, or rather lack of decisions, regarding her illness had a significant impact on her illness trajectory. These implications will become clear during the course of this chapter. Upon discovery of the fast-growing lump in her right breast, Lily *did not* immediately seek treatment. In fact, she avoided the experience for years. She had no previous diagnosis of cancer, but Lily has a family history of breast cancer. Her mother was diagnosed with breast cancer when she (Lily) was 18 years old. Lily spent most of her childhood years in a single-parent home and became, by default, her mother's support system.

Lily told me that her childhood years were "not pleasant" and reported her experience of her mother's breast cancer as "extremely traumatic". Lily reported that her own diagnostic and treatment experiences left her feeling disempowered, violated and degraded. She compared her experience of chemotherapy to her idea of dying. She made an analogy of her initial experience at the hospital to that of being in a Jewish concentration camp: feeling desolate, vulnerable, demoralized and dehumanized. The findings in section 4.4 show the significant contribution of Lily's narrative of her experiences to this study.

4.3 Idiographic commitment

Emphasizing the idiographic commitment to Lily's study enabled me, as the researcher, to focus on distinctive features of Lily's experiences rather than general findings (Pietkiewicz & Smith, 2014). I was committed to doing an in-depth exploration of Lily's personal experience of breast cancer as well as the meanings she attributed to this experience. Both the analytic process and the interpretative approach of IPA allowed me to highlight these distinctive idiographic features. Lily's distinctive idiographic features are presented in Box 4.1.

Box 4.1 Idiographic commitment overview

- Parental influence: The significant influence of Lily's relationship with her mother and the profound impact her mother's experience of breast cancer had on her own experience. The parenting practices negatively shaped Lily's approach to her own breast cancer diagnosis, treatment, and meaning-making.
- Experiential avoidance: Lily avoided the diagnosis experience by means of delaying actions. This was a salient feature in Lily's breast cancer experience.
- Diagnosis: Lily delivered her own diagnosis, expressing the actual words even before the doctor did, and comforting the doctor. This indicated the importance of sense of agency ('I can change the world in certain ways') and personal identity, more specifically autobiographical identity ('I am the person living the narrative of my life') as well as conscious identity ('I am the author of my subjective experience') (Kubie, 2014).
- Treatment: Lily compared her treatment experience to being in a Jewish concentration camp. In response to this, I implemented the innovative use of metaphorical interpretation in reference to treatment, e.g. "*...it felt like being in a Jewish concentration camp*" and "*I felt like a dead man.*"

- Meaning making: Lily lived her life in increments of six months and avoided making plans beyond six months. Lily, therefore, had no future expectations in order to avoid or delay possible disappointments. Lily's incomplete acceptance of her breast cancer experiences limited optimal meaning-making practices.

4.4 Findings

The in-depth analysis of Lily's study consequently led to the emergence of a single comprehensive psychological concept of what it means to live with breast cancer, namely 'Loss of Sense of Personal Identity.' Sense of Personal Identity includes the components of personal identity, namely autobiographical identity, sense of agency, beliefs, conscious identity, body identity and social identity (Kubie, 2014). Consequently, I will discuss the following four supporting concepts:

- Lily's subjective perception of breast cancer
- Lily's subjective experience of breast cancer diagnosis
- Lily's subjective experience of treatment
- Lily's meaning-making

Following is a narration of the interaction between my interpretative actions and Lily's rendition of her breast cancer. Finlay (2008) stated the following: "However rich and comprehensive, any one analysis is, inevitably, incomplete, partial, tentative, emergent, open and uncertain" (p. 6). The unique findings that emerged from Lily's interpretative phenomenological analysis should therefore not be viewed as indisputable. These findings are my personal understanding and interpretation of Lily's breast cancer experience.

4.4.1 'I am not my mother': Lily's perception of breast cancer

Interpreting Lily's understanding of her own breast cancer experience led me to conclude that Lily's experience was threaded with avoidance tactics. These avoidance tactics

could have been rooted in distress and fear, more specifically fear of being like her mother. Lily reported: “I *swore* I am never going to get cancer because I do not want to be like my mother.”

Ek het net gesweer ek gaan nooit kanker kry nie, want ek wil nie...
soos my ma wees nie.

Lily’s initial experience (as a teenager) with breast cancer had a profound impact on every aspect of her life. Lily emphasized her refusal to be like her mother, and she “*swore*” that cancer was never going to happen to her. In this situation, the use of the word “*gesweer*” [swore], referred to Lily’s promise to herself that she will not become her mother. This declaration became the foundation on which Lily based her perspectives and perceptions about her own breast cancer reality.

Lily explicitly used the word ‘traumatic’ to describe her experience of her mother’s breast cancer diagnosis. Lily reported: “it was a very traumatic experience for me when my mom got *it* because she kept on saying: ‘the doctor says I might die’...”

Dit was vir my ‘n baie traumatiese ondervinding toe my ma dit gekry het
want al wat sy gesê het was: ‘Die dokter sê ek gaan dalk dood gaan’.

In my interpretation, Lily’s mother’s response to her own diagnosis was one of *thanatophobia* (fear of death). At the age of 18 years old, Lily had to come to terms with the possible death of a parent, which probably left her feeling vulnerable and psychologically distressed. Anticipating further losses of parental emotional and physical availability, especially in the light of her mother’s continued referral to her dying, Lily reported that she experienced psychological distress. Her distress was probably exacerbated by her mother’s avoidance to talk about her own breast cancer. Lily mentioned: “you know, we did not really speak about *it*.”

Jy weet ons het nie regtig gepraat daaroor nie.

Inadequate disclosure left Lily with little information other than her own experiences to construct her reality and sense of identity. Both of these were therefore grounded in and greatly influenced by her own ideas, thoughts, and perceptions of her mother's breast cancer. Faced with mortality, life-changing threats and decisions, Lily responded with coping strategies such as avoidance tactics, thought suppression and extreme denial. Despite her known family history of breast cancer, Lily reported: "I never went for mammograms or breast-checkups."

Dis hoekom ek nooit gegaan het vir mammogramme nie, ek het nooit gegaan vir bors-checkups [sic] nie.

I thought Lily's attitude to be paradoxical because, in struggling with her fear of being like her mother, Lily *became* her mother. She resembled her mother as follows: A fearful, divorced woman in her early forties, with a teenage daughter, receiving a breast cancer diagnosis and treatment. Lily's admission of her breast cancer would probably mean admitting to failure and loss of conscious identity. It is clear from the description that parenting influences and practices greatly impacted on Lily's sense of personal identity and coping strategies. I concluded that this was Lily's experience of her disease trajectory.

4.4.2 'The elephant in my head': Lily's experience of breast cancer diagnosis

One of the characteristics that stood out from the interview with Lily regarding her breast cancer diagnosis was (again) her avoidance of the experience. The idea of breast cancer probably generated feelings of fear and trepidation in Lily. In Lily's words: "I thought if I ignore *this* long enough, *it* will not happen to me, I thought *it* would just disappear."

Ja, want ek het net gedink as ek dit lank genoeg ignoreer dan sal dit nooit met my gebeur nie...en ag ek het maar net gedink dit sal weggaan...

Lily's unwavering belief in her health, or rather the absence of cancer, continued even after the discovery of a lump in her right breast in 2006. I interpreted this belief, or denial, as experiential avoidance. Lily stood firm in her belief that the lump in her breast was not cancerous. Lily kept referring to her breast cancer as "*it*" and "*this*"; these non-descriptive words mitigate the certainty and gravity of her breast cancer and were, in my opinion, indicative of her avoidance of the actual experience. In my experience, culturally, the word 'cancer' often connotes death and stigmatization. Her choice of words, therefore, reflects Lily's own fear of death and possible stigmatization.

Notwithstanding the evidence of a positive mammogram showing a cancerous tumor of 6 cm, Lily still did not except that there was a strong possibility that she had breast cancer. Lily reported: "I thought *it* would just go away."

Ag ek het maar net gedink dit sal weggaan.

I thought that Lily made an effort to avoid the breast cancer diagnosis experience by suppressing her thoughts about breast cancer. Acknowledging that she had breast cancer was probably an acknowledgment of personal failure. In my opinion, a diagnosis of breast cancer would deprive Lily of her sense of agency as well as her conscious identity.

Lily mentioned a modification of her identity, pre-breast cancer as opposed to post-breast cancer. She reported that 'before breast cancer' she used to be 'a very private person' and 'now it was completely different.'

Ek was voor ek borskanker gehad het was ek 'n baie privaat mens...
dis nou heeltemal anders.

Lily's sense of being, her autobiographical identity, her body identity and her conscious identity were about to be altered and/or replaced. Reflecting on this statement, led me to conclude that Lily experienced extreme loss of personal identity. Lily was painfully aware of this potential life transition. This transition could lead to Lily experiencing feelings of diminished self-worth, loss of self-esteem and confidence. Lily adopted an attitude of apathy, describing how little she now cared about her privacy. Lily reported: "In the beginning it was terrible, it was one of the most terrible things, but I got used to it, it does not bother me anymore."

Ek is gewoon daaraan ek is nou nie meer gepla nie maar in die begin was dit vir my baie erg, dit was seker vir my een van die ergste goed gewees.

Before she was diagnosed with breast cancer, she guarded her nudity to the extent that even her husband was not allowed to see her naked. Lily stated that medical interventions related to her breast cancer stripped her of her sense of self-worth, personal agency, and body privacy. In Lily's words: "...because, if you were in a training hospital, everybody looks at you, the laundry guy, that, anybody that walks pass can look while you are being examined, they do not really care."

Want as jy in 'n training hospitaal was nê dan kyk almal na jou, die ou wat die wasgoed was, die ou wat die kos kook die— enige iemand wat in die gang verby loop toevallig is hulle besig om jou te ondersoek nê, hulle gee nie eintlik rerig om nie, hy kan ook maar kyk, so...

Medical treatment in a government hospital, or in Lily's words, "a training hospital," made her feel less of a human being. Interpreting Lily's rendition of time spent in a government hospital made me realize the importance of medical professionals' understanding of human agency and to guard against provocation of helplessness. Lily reported a different experience,

such as humiliation and demoralization. In my interpretation, Lily felt devalued as a person, more like a ‘body anyone can look at.’ Loss of sense of personal identity probably created self-doubt in Lily, which in turn led to fearfulness, personal insecurities and, therefore, experiential avoidance.

On the day Lily was to receive her diagnosis, her husband offered to accompany her to the breast clinic. She declined his offer, assuring him that “it was probably going to be something stupid, do not worry about it, you don’t have to come with, so I went on my own.”

Ag nee man dis seker net ietsie stupids, moenie worry daaroor nie,
jy hoef nie saam te gaan nie, so ek het allenig [sic] gegaan.

Facing a possible life-changing diagnosis, Lily downplayed the enormity of the experience by using a diminutive ‘*ietsie*’ (something very small) and the word “*stupids*” (something silly). These descriptions, “something small,” “stupids,” and “it,” once more, reflected Lily’s mitigating tactics. I interpreted this as evidence of Lily’s experiential avoidance and, in my opinion, extreme pathological denial. Lily’s description of her receiving the actual breast cancer diagnosis revolved around the doctor acting like a ‘young little girl’ who ‘had tears in her eyes’ and ‘could not get the words out.’

’n Doktertjie, so ’n jong meisietjie, ek het haar so jammer gekry sy want
sy was so—en sy het trane in haar oë gekry en sy kon nie praat nie, dit
was soos in: “uh uh uh” sy kon nie woorde uitkry nie...

Ironically, despite Lily’s extreme avoidance of receiving a diagnosis, she herself became the messenger of bad news, also comforting the doctor. In an unexpected turn of events, Lily told the doctor: “it is okay, I know it is cancer, it’s all right, don’t worry.” Lily was

reclaiming her sense of agency and personal identity by taking control of her experience by delivering her own diagnosis.

Toe sê ek vir haar: “dis okei, ek weet dis kanker, dis orraait, moenie worry nie.

My interpretation, expressing the actual words, “I know it is cancer,” was Lily’s first step in accepting her fate. I thought that expression, as a form of acceptance, was an empowering experience and an important part of Lily’s coping strategies. Sense of agency also meant a reversal of roles, changing from being a victim to a survivor. I came to view, through Lily’s descriptions, that a diagnosis of breast cancer encompasses loss of personal identity, which includes emotional losses, loss of social identity, change in beliefs, loss of physical identity (more prominent in treatment), learning new coping strategies and ‘learning’ to accept the new altered you.

4.4.3 ‘An incredible devastation of being’: Lily’s experience of treatment

Lily drew a comparison between her treatment experience at X-block and being in a Jewish concentration camp. Lily received her diagnosis at the breast clinic of the fifth floor of the hospital, but the actual radiation treatment center, X-block, was located in a separate building outside the hospital. After receiving the diagnosis, the patients, including Lily, were escorted by an attending doctor to the treatment center. Lily gave a vivid description of “the whole small group (of patients) walking across the small field, ” and each patient appeared (in her mind) to be “scared, fearful and whatever.”

Want jy gaan mos nou so oor die veldjie..., so dan loop ons nou so hele ou groepie en almal is nou so bang en verskrik en watookal [sic], maar ons gaan nou soontoe.

Even though Lily's description was inclusive of the group, I thought Lily's account of the experience was probably truthful of her own distress. Lily reported: "we stood in the passage, and he (doctor) said that before processing us... you know it almost sounded to me like a Jewish concentration camp... it was that scary to me".

Gaan staan ons daar in die gang toe, sê hy (dokter) okei, voor hulle ons nou begin process, jy weet, dit het amper geklink vir my soos 'n Joodse konsentrasie kamp...dit was vir my so scary gewees.

Lily described the experience as "so scary." I interpreted, Lily experienced intense psychological distress. She probably envisioned herself a prisoner, being held captive by a disease from which there was no escape. In my opinion, she felt she had no sense of agency and no sense of conscious identity. Lily described that at the time she had little knowledge regarding the treatment trajectory. She 'knew nothing about chemo, radiation or a mastectomy.'

En toe het ek nog niks geweet van chemo af nie, ek het niks geweet van bestraling af nie, ek het niks geweet van mastektomie af nie.

Lily's reality at that specific time was constructed in past experiences related to a similar experience with the diagnostic procedure, the needle biopsy, and more salient, her mother's breast cancer experience. She reported the experience as 'horrible'; she described her mother's mastectomy as similar to 'organs being removed from one's body'. In my opinion, Lily's perception of her limited understanding of available information regarding the course of treatment, or (perceived) lack of information, created a sense of insecurity as well as a perceived lack of control. Both the insecurities and perceived lack of control undermined her personal identity.

Lily specifically mentioned that, retrospectively, she would have wished to be informed, because knowing what to expect would have increased her tolerance level and sense of agency. Lily reported: “ For me personally it would have been better if I knew beforehand because I am someone who copes better when I know what to expect, I informed myself by doing research on the internet and reading.”

Vir my persoonlik sou dit beter gewees het want ek is iemand wat daarvan hou ek, ek cope beter met goed as ek voor die tyd goed weet, dis ook hoekom— ek het myself— ek het verskriklik baie gelees, ek het op die internet navorsing gedoen.

Lily did not feel empowered. Instead, she felt humiliated and degraded. She did, however, take action to empower herself through reading and research on the Internet. Lily discerned her initial experience of treatment as not only lacking in information but as an embarrassing introduction to her treatment experience. I thought that this impacted negatively on her perspective of the disease trajectory and her overall well-being and identity. Lily experienced lack of respect, feeling dehumanized and demoralized, as mentioned before. She gave a graphic explanation of the side effects related to chemotherapy. Lily reported that she “was like a dead man, the first three or four days, not being able to function at all.” Lily stated that she felt incapacitated by the treatment.

Dit het my so geïncapitatie [sic] om incapitatie [sic] dat ek kon nie funksioneer nie, ek het die eerste drie, vier dae nadat ek chemo gehad het was ek soos ‘n dooie mens.

Lily described her chemotherapy as ‘the most horrible feeling.’ She again had thoughts of death and dying. Death would have been acceptable in comparison to ‘her eyes overturning in her head’ and her ‘lungs freezing.’

Die een middel wat hulle vir my— as hulle dit begin in my drip in sit het, het dit gemaak dat my oë omgedop het, dat ek daar gesit het en gedink het ek gaan vrek, jou longe word so ys-vries koud, dis die horribleste [sic] gevoel.

Lily reported one ingredient, which was part of her chemotherapy, to have “horrible” side effects. Lily researched this specific product (“middel”) on the Internet and found it to be a diluted version of a similar product used to eliminate Jews. Lily stated: “ I read about those products en some of them is actually used to murder Jews.”

Ek het gaan op lees oor daai middels en sekere van daai middels is actually gebruik om die Jode dood te maak.

In my interpretation, this self-researched information did not diminish Lily’s anxiety. Instead, she became more fearful of her treatment and the possible side effects. Her (perceived) knowledge probably enhanced her sense of loss of agency, loss of personal identity as well as fear of death. Anticipating death or more salient in this situation, anticipating loss, probably created existential questions for which Lily had no plausible answers. In anticipation of the physical loss of her breast, Lily experienced anticipatory grief, including symptoms such as sadness, anxiety, poor concentration, guilt, and fear, to name a few. I thought that the grief and fear associated with that loss probably added to her slow recovery and healing.

In the following extract, Lily’s description expressed her fear of losing her breast. Lily mentioned three aspects: firstly, the mastectomy, secondly, “*not* because I consider my boobs to be sacred” and thirdly, “it was such an invasion of my privacy, I could not think of anything worse’.

Dat hulle net nie my boob hoof af te sny nie, nie omdat ek... heilig is op my boobs of dit nie maar dit was vir my so 'n invasion van my privacy gewees nê, dit was vir my so...ek, ek , ek kan nie dink aan 'n erger ding.

I concluded that Lily's actual words, as seen in the extract above, contradicted her true feelings. Lily reported the violation of her privacy to be more salient, but in my opinion, the desecration of her body and loss of body identity were critical events. Losing a breast was a life-altering experience for Lily, taking into account her rendition of her mother's diagnosis and treatment. Confronted with a similar situation, Lily probably experienced apprehension of the difficulties facing her life and personal identity. The permanency of an altered life caused by breast cancer resulted in Lily's experiencing psychological distress and loss of personal identity.

Lily described the image of herself in a mirror as being 'lopsided,' 'handicapped' and 'disgusting.' Her maimed body became the constant reminder of all the losses she suffered. These losses included loss of identity, loss of femininity, loss of motherhood, loss of time, loss of occupation, loss of belief, loss of dignity and loss of respect and recognition.

En elke keer wat ek vir myself in die spieël kyk dan is dit vir my—
ek is lopsided [sic], ek is gebreklik, jy weet, dit is vir my net vieslik.

Lily reported that she did not consider herself acceptable according to socio-cultural standards. In my opinion, breast cancer impacted on her sense of personal identity. Making sense and finding meaning in the breast cancer experience was critical for Lily's survival of this life-altering challenge.

4.4.4 'An eternal pondering': Lily's meaning-making

It was my interpretation that Lily's meaning-making practices were impacted by her extremely negative experiences of both breast cancer diagnosis and treatment. Some of these

(perceived) experiences already existed in Lily's construction of past cancer-reality and contributed to her present cancer-reality.

Lily spoke with conviction about her breast cancer experiences, social support from friends, her growing faith, and a healthy lifestyle. She conveyed an attitude of acceptance and being positive, *but* was adamant that she has no future prospective beyond six months. She lives her life in increments of six months, from one follow-up consultation to the next, and has been doing so for the past 5 years. Lily reported: "the six months increments, every time it feels like I am given a new life, I feel happy to know that I have received another six months."

Die ses maande inkremente wat ek, wat ek kry elke keer is vir my elke keer soos 'n nuwe lewe, ek voel so happy as ek daar wegstap en ek weet ek het nog ses maande.

Construing Lily's interpretations and statements I found many contradictions, which I thought to be an important aspect of her (less successful) meaning-making efforts. Even though Lily appeared 'happy' she also reported: "I don't think, I do not make plans, it's as if I build boundaries around myself for protection, in case I receive bad news."

Dink ek niks meer nie, ek beplan nie vir goeters nie ek ek uhm, dis amper asof ek soos boundaries om myself stel om myself te beskerm deur in geval daar iets is.

In my interpretation, positivity is more than the verbose expression of happiness. I thought that Lily's perspective of "six months increments" and "protective boundaries" did not encompass a positive perspective. Lily mentioned "feeling happy" and "a new life" after each consultation. I interpreted that this feeling of happiness was not intrinsically generated but circumstantial and temporary. This led me to conclude that Lily avoided having a thorough understanding of her breast cancer; neither did she fully accept her breast cancer.

Towards the end of the conversation, Lily disclosed for the first time that, for her, “acceptance was an enormous battle, not acceptance of cancer, but accepting that she was going to lose her breast.”

Dit was vir my ‘n verskriklike groot stryd gewees om te aanvaar, nie die feit dat ek kanker gehad het nie, die ergste vir my van die hele proses was, dat hulle my boob moes afsit.

She implied that accepting the loss of her breast was an extensive process and challenging experience. Even though Lily knew that she had to accept her fate in order to make sense of this experience she reported: “I constantly prayed and prayed, I did not pray not to have cancer, I knew I had cancer, but I asked God to make something happen to prevent having my boob cut off”.

Ek het die healtyd net gebid en gebid, ek het nie gebid dat ek nie moet kanker hê nie, ek het geweet ek het kanker maar ek het net vir die Here gevra, kan Hy nie asseblief net dat daar iets gebeur dat hulle net nie my boob hoef af te sny nie.

From my interpretation, Lily attempted unsuccessfully to cope with her breast cancer by firstly, avoiding the diagnosis, secondly, through reliance on external controlling factors such as clinicians to save her breast and thirdly, by means of spiritual transcendence. Lily admitted that she was not a religious person prior to her breast cancer diagnosis but experiencing a life-threatening illness prompted a different perspective.

Throughout the conversation, Lily disclosed different ways of coping with the diagnosis and treatment. One strategy she thought effective was her sense of humor. Lily reported: “Luckily I have a good sense of humor, I tried to make a joke of everything because that was the only way I could cope.”

Gelukkig het ek 'n baie goeie sin vir humor en ek het alles probeer 'n grap van maak en ek het— want dit was die enigste manier om daarmee te cope.

I contemplated the effectiveness of humor as a coping mechanism in Lily's case. Her use of humor could reflect as a feature of personal resilience or as means of detaching and distancing herself. In my opinion, an important aspect of coping is realization followed by acceptance. Lily mentioned a moment of insight: "I came to a standstill, thinking by myself, where am I heading, is this really what I want, is this really who I am?"

Ek tot stilstand gekom eendag en toe dink ek by myself: Waar heen is jy oppad, mevrou" is dit wat ek wil hê, is dit wie ek wil wees.

Lily's self-doubt and loss of self-value threaded through her personal identity, her beliefs as well as her social identity. Upon realizing the value and salience of the supportive roles of her husband and daughter throughout the disease trajectory, Lily stated: "I just decided that I am going to fight, I am going to fight until I can not fight anymore."

Ek het net besluit ek gaan veg en ek gaan veg tot ek nie meer kan veg nie en ek wou nie gehad het sy moet sonder 'n ma groot word nie.

Lily's reason for living was personified in the parental role of being a mother for her daughter. Lily mentioned that she: "did not want her daughter to grow up without a mother." In my interpretation, Lily reflected on the time she was young, vulnerable and without a supportive parent. I thought that this realization made Lily feel validated and enhanced her idea of self-worth in her role as emotional provider for her daughter and husband. In my opinion, finding worth through self-transcendence enhanced Lily's capacity for meaning-making.

Lily constructed meaning in her breast cancer experience on her own terms, by living in the moment. I interpreted Lily's interpretation of her breast cancer in the context of loss. Lily's loss of personal identity projected in various ways throughout her disease trajectory and, in my opinion, her loss of personal identity was, and still is, evident in survivorship.

4.5 Conclusion

Breast cancer is both visible and visceral, and for Lily, the visible, as well as the invisible changes interrupted her life and left her with no sense of agency. Loss of sense of agency reflected in Lily's loss of personal identity, which impacted on her well-being throughout the disease trajectory. Being challenged by adversity and life-threatening circumstances such as breast cancer probably taught Lily to live mindfully and appreciate the value of time. Lily's vivid descriptions of her breast cancer diagnosis and treatment experiences provided me with invaluable knowledge and information. Even though this information and findings were my interpretation of Lily's interpretation of her personal experiences, it formed part of unique specifics that are part of shared humanity.

CHAPTER 5

ANALYSIS AND FINDINGS:

MINA

5.1 Introduction

The findings, as presented in Chapter 5, are my personal understanding and interpretation of Mina's (pseudonym) breast cancer experience. The aim of this chapter is the in-depth exploration and interpretation of Mina's subjective experiences of her breast cancer diagnosis and treatment. The first section describes Mina in context. This description of Mina's background presents the reader with partial insight into her circumstances. Mina's account of her breast cancer experience is in keeping with Heidegger's idea of 'Dasein', which in this context refers to Mina's awareness of her changed personal identity and mortality (Wheeler, 2016).

The second section highlights the idiographic commitment to the findings of Mina's case study. Following this is the findings section, which includes four concepts, namely Mina's subjective perception of breast cancer, Mina's subjective experience of breast cancer diagnosis and treatment, as well as Mina's meaning-making.

5.2 Mina in context

Mina is a 54-year old ill-educated, Afrikaans-speaking woman who has been diagnosed with stage II breast cancer (right breast) in 2011. She has no known history of breast cancer, and she reported that this experience was her first encounter with cancer. A diagnostic mammogram also indicated metastasis to her left breast. Her course of treatment included chemotherapy, a bilateral mastectomy, radiation, and medication.

Mina's first biopsy (right breast) was done at a government hospital in a nearby town. The results of the biopsy indicated breast cancer and Mina was referred to Tygerberg Hospital.

Mina had previous consultations at the breast clinic. After the birth of her son, Mina reported that her breasts produced green-colored milk.

Mina was unemployed at the time of the interview; she occasionally does domestic cleaning and has done so for the past 15 years. She only received her first social grant from the government a month before the interview (June 2016). She is the primary caregiver of her granddaughter, who is eight years of age and resides with Mina in a rural, low-income housing establishment. Mina has five grandchildren, but she mentioned a special connection to her granddaughter who is the child of her daughter.

Mina reported that her husband and two of her sons passed away the previous year (2010). She has no living parents; her father passed away in 2006, and her mother passed away in 2010. I mention these deaths to emphasize Mina's continuous subjection to mortality, which evidently impacted on her life-world and, therefore, her sense of personal identity.

She has two brothers and three sisters, but she is not close to her siblings. Mina receives no support from her family. She has two other living children, a son, and a daughter. According to Mina, she has a good relationship with both her children although she expresses difficulty discussing her breast cancer diagnosis and treatment with them. Mina's (perceived) lack of social support was an important factor in her experience.

Mina gave a compelling account of her past relationship and history with her daughter. During the course of one week, Mina's received news (on a Wednesday) from the local clinic that her daughter of 15-years was pregnant. Mina reported that, at the time, she was devastated by the news of the pregnancy. This event had a significant impact on Mina's frame of reference regarding her own realities at the time. On the Thursday, of the same week, Mina received her breast cancer diagnosis. From Mina's accounts, it was evident that these two incidents irrevocably disrupted the course of her life. Metaphorically speaking, she used her daughter's pregnancy, specifically the physical pain pertaining to the process of labor to describe her

thoughts and feelings regarding her own breast cancer diagnosis. Even though Mina gave a negative account of her experience of her daughter's pregnancy, she rendered a contrasting account of the birth of her granddaughter. Mina delivered her granddaughter and disclosed elation and peace upon receiving the baby. These events played a pivotal role in Mina's breast cancer experience.

She perceives herself as a proud, independent and extremely spiritual person. Throughout the interview, Mina often referred to the Deity as the creator and phenomenal being. Mina's primary meaning-making practices revolved around her religiosity and spirituality.

5.3 Idiographic commitment to Mina's study

The primary goal of this IPA study is the in-depth analysis and interpretation of Mina's particular experiences of breast cancer, as well as her personal understanding of what it means to live with breast cancer. These distinctive idiographic features are presented in Box 5.1.

Box 5.1 Idiographic commitment overview

- Diminutives: Mina's use of diminutives (e.g., a little bit of a cancer) probably reflects her mitigation of the severity of breast cancer.
- Surrender: Mina accepted breast cancer as fate by surrendering to God.
- Diagnosis: Receiving a diagnosis was an emotionally painful moment; she compared the experience to labor pains.
- Treatment: Mina felt deprived of her femininity after her mastectomy; she reported feeling like a man.
- Meaning making: Mina's primary coping strategy was through spiritual transcendence and religiosity.

5.4 Findings

The analysis of Mina's study led to the emergence of a single overarching psychological concept of what it means to live with breast cancer, namely loss of sense of personal identity. Sense of personal identity includes the following six components of personal identity: autobiographical identity, sense of agency, beliefs, conscious identity, body Identity and social identity (Kubie, 2014). Subsequently, I will discuss the following four supporting concepts, as well as the significance of personal identity as it pertains to these concepts:

- Mina's subjective perception of breast cancer
- Mina's subjective experience of breast cancer diagnosis
- Mina's subjective experience of treatment
- Mina's meaning-making

Smith and colleagues (2009) stated: "There is no such thing as a 'perfect' data collection event, and no version of events which is 'the truth'" (p. 60). With this in mind, an interpretative account is drawn from the single interaction between Mina and myself. The unique findings that emerged from Mina's interpretative phenomenological analysis are ambiguous (open to more than one interpretation) and merely reflect my intimate exploration and interpretation of Mina's breast cancer experience.

5.4.1 'The soul always knows': Mina's perception of breast cancer

Ongoing throughout the interview I identified two prominent occurring features in Mina's account: first, Mina's fatalistic perspective and second, Mina's use of diminutives. Mina reported with unabated conviction that her breast cancer experience was part of God's plan for her life. When I asked Mina about her previous experience with breast cancer, Mina reported: "I did not even know what cancer was, where do we find it, what is it? – Is it a small plant that grows... and it roots [sic]?"

Ek het nie eers geweet wat kanker is nie, Waar kom ons aan kanker,
wat is dit? – is dit 'n plantjie wat groei...en hy wortel?”

Mina’s comparison of her breast cancer with “a small plant with roots”

(plantjie en dit wortel) and her confusion pertaining to her discovery of the lump, “It was deep [sic]...I don’t know what happened”, could possibly be attributed to her confessed lack of knowledge about breast cancer. I interpreted Mina’s use of the word “diep” (deep), to be a reflection of the intensity of her emotions and feelings, as well as the magnitude of this experience. From her words, I concluded that Mina probably did not have the necessary vocabulary to describe her cognitive experiences of breast cancer comprehensively.

Dit was diep...ek weet nie lekker wat het daar gebeur het nie...

Based on what she told me, Mina knew about breast cancer but never contemplated a personal experience of breast cancer, hence her perceived lack of knowledge. Mina’s first response upon finding a lump was to pray: “Oh Lord, You have to now – I have to go to work.” I inferred that this statement could be viewed as part of her fatalistic approach to life, which surely had an effect on her sense of agency and personal identity. I concluded that Mina willingly relinquished control to God in an attempt to make sense of her experience. Mina did not accept the possibility that she could be a victim of breast cancer. She stated: “this must be mammary (milk) glands, I’ve heard about it from the ‘Mamma’ Clinic when I came with my breasts because my breast milk was green [sic]”

Dis seker melk kliere [sic], want dié het ek al van voor ek gehoor
hier by die Mamma Kliniek met my borste want my melk was groen.

At the time, Mina constructed a reality based on past experiences and possibly engaged in inferential thinking. She stated that she had knowledge about “green milk” and this was a concept she understood. According to existing literature, green breast milk could be the result of certain foods such as green vegetables, herbs or vitamin supplements. Mina based her decision to go to the hospital on her idea of “green milk” being an acceptable and manageable situation. Decision-making probably enhanced her sense of agency. Mina disclosed: “so I went with the *small lumps* and I hoped for the best.”

Ek het maar gegaan met die ou klontjies en gehoop van die beste.

Mina often used diminutives when referring to aspects of her breast cancer. In this statement, she spoke about “small lumps” (klontjies). Mina also referred to her breast cancer as “a little bit of a cancer” (“’n klein bietjie van ’n kanker”). I interpreted Mina’s narration as mitigation of the perception of her breast cancer. It could be an attempt from Mina to minimise the severity of a life-threatening diagnosis in an effort to make this experience more bearable. At the time, before receiving the final diagnosis, Mina appeared apathetic (passive and emotionless) and “hoped for the best.”

Contradictory to her appearance, Mina probably experienced loss of autobiographical identity, loss of conscious identity and loss of sense of agency. Mina’s beliefs regarding her present reality were challenged by circumstances over which she had little control. I conclude that Mina’s perception of breast cancer was supported by her fatalistic approach towards not only her breast cancer but also her life in general.

5.4.2 ‘Pain is remembrance’: Mina’s experience of breast cancer diagnosis

Mina’s multiple diagnostic interventions (mammogram and two needle biopsies) were done at a government hospital in a nearby town. The first time Mina was told she had a

“growth on her breast,” she reported: “ and I wondered, I was too scared, ashamed to ask the people what a growth was.”

Eerste keer toe sê hulle vir my ek het 'n gewas op die bors en en het gewonder, ek was te bang skaam om vir mense vra wat is 'n gewas.

Mina reported feelings of anxiety and shame for her (perceived) lack of knowledge as if she was at fault for not knowing what a “growth” was. I assimilated that these feelings of shame and anxiety attributed to, and probably intensified, Mina’s existing fears about her potential illness and uncertainties regarding a possible fatal diagnosis (the “little lumps”) of breast cancer. Mina disclosed that she eventually asked the doctors and the sisters about the “growth” and “ they did not want to talk to me, telling me they do not want to give me false hope; they told me I need to come again for another small test, again for a small test.”

Ek het die dokter gevra en ek het vir die susters gevra en hulle wil nie met my praat nie. Hulle sê hulle wil my nie valse hoop gee nie, ek moet maar weer vir 'n toetsie kom. Weer vir 'n toetsie...

Even upon asking the hospital personally, she did not receive an informed answer regarding the “growth.” Mina spoke about the doctors and sisters not wanting to convey “false hope” and reported they requested a second “small test.” At the time, Mina was, in all probability, experiencing psychological distress. She most likely experienced the “not false hope” message as rejection, which resulted in feelings of hopelessness and helplessness. I concluded that these feelings contributed to her existential distress. I also deduced that the lack of information about her illness, as well as vague reports about the test results, created a sense of demoralization and possible feelings of dehumanization. Mina, again, mitigated the severity of her experience by referring to the diagnostic interventions as “a small test” (toetsie).

When I asked Mina if she could describe her thoughts and feelings pertaining to her breast cancer diagnosis, she used a powerful metaphor. This unconventional metaphor effectively described her experience of breast cancer diagnosis. In an effort to explain the enormity of this breast cancer experience to her daughter, who was 15 years old at the time, Mina referred to the daughter's pregnancy, specifically the physical pain of giving birth. Mina reported that she was devastated by the news: "but when mommy heard you were pregnant, that was the most painful (sore), most painful in my body [sic]"

Dan mamma gehoor het -- Jy verwag... dit was die seerste, seerste in my liggaam.

During my time as a midwife, patients described labor pains as excruciating, unbearable and intensely searing. I comprehended that Mina's emotional pain upon hearing about her daughter's pregnancy, and her own breast cancer diagnosis, caused her to experience powerful negative emotions and feelings. Mina described the experience as follows: "Can you see? It is nice to eat a banana but if that banana comes out like a pineapple, full of thorns - can you see how painful it was my child – that was how mommy felt when mommy heard that mommy had cancer".

Kan jy nou sien? Om 'n pineapple te -- 'n piesang te eet is baie lekker maar as hy uitkom kom hy soos 'n pineapple vol dorings uit – dit is nog vir haar gesê...Toe sê ek nog vir haar kan jy nou sien hoe seer is dit my kind...Sien jy dat wat mamma gehoor het mamma het kanker.

It is apparent that Mina experienced emotional turmoil, disappointment and was in a state of shock. Mina's expressed disappointment was probably directed at herself more so than at her daughter. I was of the opinion that Mina perceived herself a failure: she failed to protect

her daughter, and she failed to protect her health. Mina gave a vivid description of the emotions and feelings she experienced the moment she received her breast cancer diagnosis: “I sat there – Ahhggh, I just – I don’t know...I just felt warm, and then I cried – You know, I felt intense hurt, that was on a Thursday. I did not know what to do or where to go, and the whole weekend I was not myself, not that I was rude or offensive, I just could not face people”.

En ek het daar gesit— Ahhggh, En ek het net— ek weet nie ek het net warm gevoel toe het ek begin huil— Weet jy en ek het oorseeer gevoel, dit was op ‘n Donderdag. En ek het nie geweet wat moet ek maak nie ek het nie geweet waarnatoe nie. Ek was die hele naweek so bietjie uhm— nie dat ek onbeskof of beledigends gewees het nie, ek was net nie myself nie. Ek kon nie mense in die gesig gekyk het nie.

Mina gave a detailed description, which I thought was remarkable given the fact that she received her diagnosis in 2011. Mina reported “feeling warm,” “oversore [sic],” confused and “not herself.” In my opinion, Mina experienced severe psychological distress that impacted on her sense of personal identity. Mina probably saw herself as a different person, one that she was not acquainted with. Mina reported: “ I looked at my breasts, twice, and I said to The Lord that only He knows why – because You want me to be Your child,”

En ek het twee kyke na my borste gegee en ek het gesê. Ag Here, U weet hoekom en waarom - U wil hê ek moet 'n kind van U word.

I interpreted Mina’s statement as surrender and a reluctant acceptance. Her personal identity and beliefs were challenged on a level Mina probably never encountered before. Mina’s disclosure of “looking at my breast, twice” led me to conclude that she might have experienced a sense of dissociation, separating her breasts from the rest of her body. This separation process could have been part of Mina’s efforts to safeguard herself and preserve her

dignity. It is clear from Mina's account that breast cancer had a significant impact on her body identity.

5.4.3 'A tolerable sadness': Mina's experience of treatment

In anticipation of her treatment, Mina became very aware of possible critical changes. Mina often made reference to one critical change, that of her physical appearance. It was apparent throughout the description of Mina's treatment experiences (chemotherapy, surgery, and radiation) that she valued her feminine appearance, which included her breasts, hair, and feet. Mina reported uncertainties regarding her treatment and described what she had seen and heard: "I did not know how it was going to be for me because I heard so many things about cancer, people lose their hair, people get thin, they can not see properly."

En ek weet nie hoe gaan ek word nie want ek het so baie dinge
gehoor oor kanker, mense se hare val uit. Die mense raak maer.
Hulle sien nie mooi nie en so.

At the time, Mina had been informed regarding her course of treatment but probably lacked information regarding the possible complications of the different treatment interventions. Mina's limited understanding and (perceived) lack of knowledge probably enhanced her uncertainty of how she would be affected by cancer. My understanding was that Mina was concerned with (her) physical appearance and how cancer would affect her body identity. Mina, in all likelihood, feared the visible aspect of cancer treatment side effects most. Mina disclosed how proud she was of her femininity: "a woman's pride is in her breasts, her hair and her feet."

'n Vrou se trots is mos in haar borste en hare en haar voete.

At the time, Mina had been informed of her bilateral mastectomy following the chemotherapy. When I asked Mina about her chemotherapy experience, she reported: “It was not a nice uh-hum..experience because there was too many of us sitting in a circle, everyone talking. I felt nauseous, and my nose had a burning sensation that lasted till my chemo ended, but what went on around me frightened me a little bit [sic]”.

Dit was nie vir my 'n lekker uh-hum... Ervaring want ons is te veel wat so sit in 'n kring nou praat daai en daai een praat. Ek het net naars gevoel en my neus het gebrand tot my chemio klaar is, maar wat rondom my aangaan maak my 'n bietjie bang maak.

Mina's description of the chemotherapy sessions conveyed an image of strangers sitting in a circle, with no privacy. Some patients were discussing their experiences; others were being sick (vomiting) and feeling nauseous. Mina reported that these sights provoked anxiety and that she felt exposed, fearful and vulnerable. Lack of privacy whilst receiving treatment and “sitting in a circle” together with fellow patients created fear and probably intensified her uncertainties regarding her physical wellbeing and body identity. Mina mitigated the experience of sharing chemotherapy with fellow patients by referring to it in a diminutive form as “a little bit” scary. Even though she mentioned feeling “nauseous,” she also compared the side-effects with “a headache for which she would take a disprin”; describing the side effects as “nothing.”

Dit was amper vir my so ... In werklik 'n kopseer dan moet ek disprin kry. Niks, niks, niks.

It was clear from Mina's account regarding chemotherapy that she managed the side effects. However, Mina reported her experience, post surgery, in the hospital ward to be a different experience. Mina gave the following account of her experience in the ward: “ Then I said: ‘No, I need to lift my arms because here I am going to die’ and that was what I did.”

Toe sê ek nee ek moet my blaaie hier oplig want vrek hier gat ek dood...
en toe maak ek so.

I concluded that contradictory to her fatalistic approach, Mina was, in fact, fearful of dying. This was the first time Mina mentioned her mortality. I interpreted that Mina's reasoning about dying prompted her to make, which was in her mind, a life-saving decision ("lifting my arms"). Mina refused further interventions and chose to leave the hospital. Her thoughts and actions were partly guided by uncertainties and unanswered questions. I discerned that Mina used intuitive reasoning in order to have some sense of agency.

As mentioned before, Mina disclosed a preoccupation with her physical appearance. I asked Mina about her feelings and thoughts following her bi-lateral mastectomy and Mina disclosed: "It makes me feel like a man, a woman without breasts...makes me feel like a man".

Dit laat my soos 'n man voel. 'n Vrou sonder - Borste laat my soos
'n man voel.

This preoccupation with her breasts or loss of her breasts and, therefore, loss of femininity and body identity, is ongoing throughout her accounts of her experience. From my interpretation, Mina experienced psychological distress, a loss of personal identity and a sense of depreciation. Mina was probably influenced by cultural and societal norms of femininity. She reported being concerned about acceptance from her child and her community, as well as the responses from "the outside-people." She also reported that she "decided to stay in the house most days."

En hoe sal my kind my aanvaar, en die buite mens? En daarom het ek baie
dae maar in my huis maar net gebly.

Mina reported a loss of feminine pride, thoughts of trepidation, as well as fear of rejection and alienation from her community. My interpretation; Mina believed her fears justified her social isolation. I concluded that Mina's cognitions were influenced by her environment as well as internalized past and present memories and experiences.

It was clear from Mina's descriptions that her breasts were an important part of her body identity. Mina's maimed body became a constant reminder of her loss of body identity and could have led to internalize antipathy. Mina probably felt devalued and depleted of her prior body identity, sense of agency and conscious identity. As a consequence of breast cancer treatment, Mina had to acknowledge and cope with an altered sense of personal identity.

5.4.4 'The audacity of hope': Mina's meaning-making

Mina's meaning-making comprised different tactics in order to explain and understand her breast cancer. Upon asking Mina about her understanding and, more specifically, the reason for her breast cancer, Mina answered: "To be honest with you, I do not know why this happened."

Om eerlik met u te wees, ek weet self nie hoekom dit gebeur het nie.

Mina "did not know" why she had breast cancer and, in an attempt to make sense of her circumstances, referred to the student doctors at Tygerberg Hospital for information. As a response, the student doctors provided limited information concerning her breast cancer, such as "hormonal problems" as a probable cause. Mina reported: "I always wondered what hormonal problems meant"

Ek het altyd gewonder wat beteken hormoon probleem.

Mina was uninformed and uneducated regarding her breast cancer. Conjecture could lead to wrongful decisions or, as in Mina's case, indifference. Mina adopted a fatalistic perspective and approach since her primary strategy to understand and make meaning was, and still is, by means of spiritual transcendence and religiosity. Mina reported: "I said, You know why, Lord, but Lord, You have to save me so that I can see myself... My heart, my soul and everything will stand firm until death separates me from a church [sic]."

Jy weet ek sê Here U weet hoekom... maar Here U moet ook myself maar red dat myself kan sien... my hart, my siel en als wil volkome vas staan tot die dood my skei van 'n kerk.

Mina reported that only God knew the reason for her breast cancer. Mina viewed God as the Creator of life and through surrendering it was expected of her to trust God unconditionally. Mina's actions could be interpreted as magical ideation and might provoke scientific skepticism. Mina could be described as a person with an external locus of control, but I experienced Mina as a religious and spiritual woman who created acceptable realities through the internalization of spiritual practice and tradition. During the interview, Mina continuously mentioned her religion: "every day I thank The Lord that I am alive, I love to pray, and I love The Bible and Psalm 23".

Maar elke dag sê ek vir die Here dankie ek leef, ek is baie life vir bid en Die bybel en Psalm 23.

In my opinion, religion and spirituality are first, personal experiences that could be representative of a person's cultural and social beliefs. I thought that Mina's religious practices played an important and supportive role in her emotional well-being. As confirmation, Mina

disclosed: “How can I not go (to Tygerberg hospital), I have already forwarded Psalm 23 – The Lord will bring me back again to you tonight...The Lord has been so good to me.”

Hoe kan ek dit los as ek dan klaar vir Psalm 23 vooruit gestuur het? - Na Tygerberg toe - Die Here bring my vanaand weer terug na jou toe...Hy was net so goed vir my gewees.

Being the spiritual person she is, Mina firmly believes in the protection of Psalm 23. Mina reported feeling secure and believed the words: “The Lord is my Shepherd: I shall not want.” I interpreted Mina’s faith as child-like, consisting of complete trust, without ulterior motives and a powerful belief in an omniscient God. Mina’s religious approach to life and her breast cancer necessitated the debate of religion as cause or effect. The question arose: Was Mina’s belief in God because she had breast cancer or did breast cancer cause Mina to believe. My interpretation was that religious cause was, and still is, interwoven with religious effect in Mina’s experience and the two concepts are not to be interpreted as separate entities.

These descriptions highlighted Mina’s belief, autobiographical identity, and conscious identity as part of her sense of personal identity. Mina explicitly stated her belief in God’s support, and she was equally clear about being averse to people. Mina reported: “I could never mix with people. I would not harm or hurt anyone, and when I die I do not want people to mourn...I want to stand man alone [sic].”

Ek kon nooit meng met mense nie. Maar ek sal niemand uhm, harm nie of seer laat voel nie en die dag as ek dood gaan wil ek ook nie hê mense moet oor my treur nie... Ek wil alleen man staan.

Even though social support is known to be an important aspect of meaning-making, Mina preferred or rather chose social isolation. I concluded that Mina did not accept this

maimed version of herself and, therefore, expected social rejection. Mina reported: “the acceptance from my children...but my children are not that bad, *but* the people outside... and that was why, most days, I stayed inside my house [sic].”

Die aanvaar van my kinders. Maar my kinders is nie so erg maar die buite mens ...En daarom het ek baie dae maar in my huis maar net gebly.

Mina probably feared being rejected, stigmatized and the cause of disappointment. We know from Mina’s narration that she experienced extreme disappointments during her life. It was also possible that she previously experienced rejection. From my understanding, Mina experienced loss of social identity and therefore loss of personal identity. My interpretation was that the pain of social rejection would have detrimental psychological, emotional and physical consequences for Mina. She reported: “From early on I told people not to feel sorry for me because I feel sorry for myself. Today you feel sorry for me and bring bags of food, but tomorrow when I really need you, then you are not there.”

Nee ek het sommer baie vroeg vir die mense -- moet my nie bejammer nie. Want ek het myself bejammer. Julle kan vandag my bejammer dan vat julle my sakke kos en klaar. Maar môre as ek hulle rêrig nodig het dan is ek nie daar nie.

I discerned that Mina’s (preferred) social isolation enhanced her feelings of low self-worth, shame, and abandonment. From my experience as a registered psychiatric nursing sister, I know that social isolation could be the cause or symptom of depression and/or social anxiety. I deduced that Mina’s social isolation, as well as her emotional isolation (hiding her feelings, unwilling to communicate), was indicative of depression.

Mina chose to have limited social interaction outside of her family. She did, however, invest in a special relationship with her granddaughter. Mina’s history with her granddaughter

goes back to the day of her birth when Mina, herself, delivered her granddaughter. I deduced that the painful memories of the past (daughter's pregnancy) were transformed into a memorable incident. She reported the following: "a little bundle of love, the baby brought peace to my heart. She is almost like a nurse to me. I love my grandchildren, I am a grandmother of five *but* she..."

'n Bonneltjie liefde, die babatjie het vrede in die hart gebring. Sy is amper soos 'n nurse vir my. Ek is lief vir my ander kleinkinders want ek het is ouma wat, wat vyf kleinkinders - maar sy...

Mina's description reflected her love for her grandchildren, but she spoke of her granddaughter of eight years old (living with her) with adoration and deep affection. Mina reported having a special bond with her granddaughter who cared for her like a "nurse". She (the granddaughter) lovingly referred to her as "old woman" ("ouvrou") as a term of endearment. Along with spiritual transcendence, her love for her granddaughter also contributed to her meaning-making by means of self-transcendence. From my interpretation I concluded that the child validated Mina's existence, providing her with a higher purpose outside of herself.

I comprehend that meaning-making is an essential component of the healing process and our well-being. Mina's narrative revealed that she chose not to avoid her breast cancer but to accept and respond to her experience through spiritual transcendence. Mina also made meaning through self-transcendence; caring and providing for her granddaughter gave concrete meaning to her life. Mina experienced validation through transcendence, which had an impact on her sense of personal identity.

5.5 Conclusion

Based on the findings presented in chapter 5, it is clear that breast cancer has a significant impact on the psychological, emotional, social and physical domains of Mina's life. The loss of a woman's breasts comprises more than just a physical loss; it also suggests a loss of body identity, loss of social identity and ultimately, loss of personal identity. In addition, the findings emphasized the importance of religion and spirituality in meaning-making practices. Mina accepted her breast cancer as fate and used the experience to enhance her spirituality. The information presented was my interpretations of Mina's understanding and meaning-making of her breast cancer experience.

CHAPTER 6

ANALYSIS AND FINDINGS:

ESTER

6.1 Introduction

Chapter 6 is my proposed investigation and interpretation of Ester's (pseudonym) interpretation of her breast cancer experience. The primary goal of this study is to explore Ester's understanding of her breast cancer from a first-person perspective.

In the next section, I deliver a description of Ester's background to provide a context in which to comprehend Ester's experiences. This description is congruent with Merleau-Ponty's perspective of embodiment, which in this case study describes Ester's relationship to her world and her precedence of her particular individual perception of her world.

The idiographic commitment to the study, as presented in the following section, allowed me to highlight both the similarities and differences that characterized Ester's breast cancer experience. In the findings section, I discuss the four concepts pertaining to her breast cancer experience, namely Ester's subjective perception of breast cancer, her experiences of breast cancer diagnosis and treatment and Ester's meaning-making.

6.2 Ester in context

Ester is a 58-year old, educated bilingual woman who was first diagnosed with breast cancer in 1998. The clinical diagnosis revealed stage I breast cancer in her right breast. At the time Ester had no known family history of cancer. However, this context changed in 2011 when her mother, then 89 years of age, received a breast cancer diagnosis. Ester reported that her mother is currently in remission and is now 93 years old. Ester also lost her brother-in-law to leukemia in 2013.

Ester was 40-years old when she received her diagnosis. She was living in a different city than her family and was a single parent to her four-year-old daughter. Ester is currently married to her second husband for 17 years. Her daughter from her previous marriage, now 23-years old, has thus been exposed to life with breast cancer for the past 10 years. I mention this specifically since Ester disclosed a very close relationship with her daughter. This relationship impacted on many of her daughter's decisions. Ester had, and still has an exceptional social support structure. Her social support includes her husband, daughter, extended family such as her parents and siblings, as well as work colleagues.

In 1998, the doctor described the tumor in the right breast as a fast-growing lump. She had a mastectomy, but no follow up treatment. In the same year, she had breast reconstruction surgery done at a private hospital in Cape Town. Ester also had a hysterectomy.

In 2002 she was diagnosed with an axillary tumor. In 2005 (47-years old) she was diagnosed with breast cancer, stage I, in her left breast. From her explanation, I gathered that this was a different type of cancer. She used the word 'spider-web'-like to describe this specific cancer. She had multiple sessions of chemotherapy and radiation and, despite treatment, the cancer metastasized to her lung and spine. After radiation treatment for skeletal cancer (ribcage), she had her second breast reconstruction surgery at a private hospital in another city. She had, therefore, had multiple cancer diagnoses (breasts, axilla, ribcage, spine, and lung), multiple cancer treatments, including two mastectomies, two reconstruction surgeries and a hysterectomy over the course of seven years.

Previously, Ester had full medical insurance and was mostly treated in private hospitals, until 2015. Due to circumstances not discussed, the medical aid company withdrew financial assistance and Ester was left with a substantial debt for her own account. Her clinician at the time advised her to continue her treatment and follow-up consultations at Tygerberg Hospital. She described her first experience in a government hospital as a 'culture-shock.' I met Ester during her

follow-up visit to the breast clinic. Ester was often emotional during the interview, especially when she reflected on situations pertaining to her daughter.

Ester's account reflected that she had suffered intense emotional trauma and psychological distress. A couple of months after her first mastectomy, her sister's husband passed away. I mention this as Ester reported the significance this incident had on her own decisions regarding her breast cancer experience and mortality.

Ester is currently employed as a lecturer at an Educational College. She had previously worked as a teacher. She stated that she prefers working with students, finding it not as emotionally taxing as working with children. She values her employment and finds security and meaning in her work.

6.3 Idiographic commitment to Ester's study

Establishing idiographic sensitivity through a detailed analysis of Ester's case study provided me, the researcher, with an awareness and insight into the particular manifestations of her breast cancer experience. These idiographic manifestations are presented in Box 6.1.

Box 6.1 Idiographic commitment overview

- Victim, survivor or chronic sufferer? Ester had been living with breast cancer, as well other cancers, for the past 19 years, since 1998.
- Mortality: Breast cancer is perceived as a mortal disease; Ester experienced the unpredictability of life and the certainty of death.
- Multiple treatments: Ester maimed body became a constant reminder of multiple losses and an uncertain future.
- Breast cancer prompted Ester to live mindfully and find meaning in everyday moments.

6.4 Findings

After investigating and analyzing Ester's case study, I deduced a single encompassing psychological concept of what it means to live with breast cancer, namely 'Loss of Sense of Personal Identity.' Sense of Personal Identity includes the components of personal identity, namely autobiographical identity, sense of agency, beliefs, conscious identity, body identity and social identity (Kubie, 2014). Consequently, I will discuss the following four supporting concepts:

- Ester's subjective perception of breast cancer
- Ester's subjective experience of breast cancer diagnosis
- Ester's subjective experience of treatment
- Ester's meaning-making

Following is an account of the dynamic process between Ester and myself whereby I attempt to understand Ester's interpretation of her breast cancer experiences. Smith et al., (2009) argued: "While we can observe and experience empathy for another, ultimately we can never share entirely the other's experience, because their experience belongs to their own embodied position in the world" (p. 25). I, therefore, do not claim to have a complete understanding of Ester's breast cancer experiences. These findings are my personal understanding and interpretation of Ester's breast cancer experiences.

6.4.1 'A captured spirit': Ester's perception of breast cancer

From the onset of the interview, it was clear that Ester had not one but multiple experiences (diagnoses and treatments) with breast cancer and cancer metastases. These experiences might have challenged Ester's disposition and way of thinking, as well as her frame of reference regarding cancer. Ester's perspectives regarding health and illness probably differ from other women's perspectives. The question arose in my mind: How did Ester eventually perceive herself: as a victim of cancer, a survivor of breast cancer or did she perceive herself as a sufferer from chronic illness?

Prior to 1998, Ester had no experience with breast cancer and stated: “I never, *never* thought about breast cancer...it was the last thing on my mind and the doctor...he did not give me any indication that it might be...”

Maar ek het glad, glad nie gedink aan borskanker nie...dit is die laaste ding wat ek aangedink het en hy, die dokter het ook vir my geen - wat is die woord, soos indikatie gegee dat dit moontlik kan.

Ester stated that she “never, never” thought of breast cancer and received no indication from the doctor regarding the possibility of breast cancer. Ester appeared to be in a state of oblivion. Being uninformed and unaware, even the possibility of breast cancer probably generated trepidation and psychological distress in Ester.

Regardless of breast cancer campaigns, from my understanding, women still perceive breast cancer to be a mortal disease. Reports from Ester indicated that stigma and myths about breast cancer were still present in our culture. Ester reported: “Because I think when you hear the word cancer, then you think it is the end for you [sic].”

Want ek dink as jy die woord kanker maar hoor, dan dink jy dit is jou einde.

Ester’s perception was that she was going to die and to me, it was clear that she experienced anxiety and fear related to this possibility. Admitting and surrendering to these thoughts and fear, of death, almost certainly made Ester acutely aware of her mortality. I thought that she probably felt threatened by the possible idea of her own death. Ester disclosed: “Almost to say; I should be the last person I’d expect to... I was only 40-years of age”.

Amper so te sê ek was die laaste persoon wat ek moes kon dink ek moet my, ek was net 40 jaar oud.

Ester's account suggested her refusal to accept the possibility of breast cancer. Cancer happened to other people. She did not fit the (perceived) criteria because she was, in her mind, too young. Thoughts about the mere probability of breast cancer and the consequence of dying marked a watershed event in Ester's world. Ester communicated a sense of debility of her human spirit by stating: "But yes, it does something to your humanness."

Maar ja, dit doen iets aan jou menswees.

Ester, in all likelihood, discerned the unpredictability of life and the certainty of death, which undoubtedly influenced her sense of personal identity. Ester's reported perception of breast cancer and her illness trajectory were intricate. It included multiple cancer diagnoses and additional physical conditions. She probably experienced multiple losses such as loss of sense of personal identity, belief, sense of agency as well as conscious identity.

6.4.2 'Sadness is a place': Ester's experience of breast cancer diagnosis

I concluded that it is critical to reflect on Ester's disease trajectory. I felt obligated to acknowledge the fact that Ester received two breast cancer diagnoses on two separate occasions, seven years apart. Throughout the seven years, and thereafter, Ester received multiple cancer diagnoses. These circumstances prompted a debate with regards to Ester being perceived, by herself and others, as a victim, survivor or sufferer of chronic illness.

When I asked Ester on the subject of experiences with cancer and breast cancer, she reported: "To tell you the truth, if I now think back, at the time, it was the last thing that went through my mind. Because in our family nobody has ever been diagnosed with cancer and so I thought this must just be a routine thing, or maybe there is just a small lump, but I never, ever, ever, ever thought that it could be breast cancer."

Om vir jou die waarheid te sê, as ek nou terug moet dink op daai stadium was dit die laaste ding wat deur my kop gegaan het. Want in ons familie was daar nog nooit iemand wat met kanker gediagnoseer was nie en ek het maar gedink ag dis maar net miskien net 'n roetine ding of miskien is daar net 'n knoppie. Maar ek het nooit, ooit, ooit, ooit kon dink dat- dat dit borskanker is nie.

Ester emphasized her incredulity by repeating the words “never, ever, ever, ever.”

Ester's vehement response could be interpreted as skeptical, which reflected her belief that breast cancer, for her, was not an option. Her response, therefore, inhibited her capacity to establish plausible justifications for her (first) breast cancer diagnosis. Upon feeling the lump, Ester reported that she phoned her sister, who took command of the situation by making an appointment for her (Ester) to see the gynecologist. Ester mentioned: “I phoned my sister, she made the appointment because she knew I would not go of my own accord.”

En toe bel ek my suster toe sê sy wel sy gaan nou 'n afspraak maak, want sy weet ek sal nie gaan nie.

I interpreted Ester's refusal, or rather reluctance, to be examined by a gynecologist as indicative of her disbelief and state of shock. Contradictory to this demeanor, Ester decided to go by herself for the needle biopsy, and the following day, for her confirmation diagnosis. Ester gave an emotional description (she became tearful) of the time when she received her first diagnosis: “ Yes, uhm, I was divorced at that stage, and—[pause] [change in voice, slight cough], I can still remember how I looked for my car. I walked and walked, probably walked past the car. I phoned my brother, but as I said, it was one hell of a shock. I could not talk...it was just too much for me; I was completely overwhelmed”.

Ja, uhm, ek was geskei op daai tyd. En- [pause] [change in voice, slight cough], ek kan nou nog onthou hoe ek gesoek het vir my motor. Ek het gestap en gestap, het seker verby die motor ook gestap. Ek het my broer gebel, Maar soos ek sê

was dit vir my 'n helse skok. Ek kon nie praat nie...Dit was vir my net te veel.
Ek kan net sê dit was vir my net oorweldigend gewees.

Ester recounted feeling emotionally overwhelmed. She was not able to act and think rationally or operate in a well-organized manner. Even though she managed to phone her brother, Ester might have experienced transient global amnesia, which was probably caused by the overwhelming emotions of anxiety, fear and intense sadness, all of which are affiliated with stressful life events. These thoughts, emotions, and feelings were constantly present, which was clear from Ester's description: "Thoughts that are always going round and round in your head, I think it is natural because you are not a machine that can just be switched off."

Gedagtes wat maar altyd in jou kop rondmaal, ek dink dis 'n natuurlike ding. Want jy's ook nie 'n masjien om jou net so af te skakel nie.

With these words, "not a machine," Ester acknowledged her full humanness, which comprised of her vulnerability, her uncertainties but also her self-respect and sense of self-worth. Keeping in mind that this narration was on the subject of Ester's first breast cancer diagnosis (right breast) in 1998, she reported her second breast cancer diagnosis (left breast) and treatment as "an uphill battle." Ester stated: "But with the left breast I had... I would say, I had an uphill battle."

Maar met die linker bors het ek 'n...sal ek sê 'n opdraende stryd gehad.

As mentioned, seven years elapsed between Ester's first and second breast cancer diagnoses. I interpreted Ester's account of "uphill battle" as descriptive of her arduous experience of her second diagnosis. She recounted that the second diagnosis "was unexpected"

(“dit was onverwags”). Upon receiving the diagnosis, she reported: “It’s almost as if your life plays before you, in the blink of an eye.”

Dis amper jou hele lewe speel in ‘n, net in ‘n oogwink deur.

Ester described her second breast cancer diagnosis as “worse than the first time.” Her statement, life can change “in the blink of an eye” probably reflected her recognition of how frail and fallible her world had become. She was compelled to think of numerous potential losses, which ultimately comprised a loss of sense of personal identity.

Following the second diagnosis Ester’s sense of personal identity, more specifically her autobiographical identity, had been subjected to changes. These changes include self-doubt, which, in this case study, reflected Ester’s questioning of herself with regard to being the same person (woman) living the narrative of her life. Ester reported: “ You stand and look at yourself in the mirror and you think, joh, is this really you?”

Staan jy en kyk jou maar in die spieël en dink, joh. is dit nou regtig jy?

In my interpretation, prior to 1998, Ester probably perceived herself as healthy, but a diagnosis of breast cancer defied her truth. Post-diagnosis, she had to reorganize her self-perception and possibly thought of herself as a victim of cancer. This thought subsequently became thoughts of being a survivor of cancer, only to be challenged seven years later. Ester, in all probability, faced an existential crisis, which left her questioning the very foundations of her life and her sense of personal identity.

Breast cancer was, and still is, part of her life and her (perceived) changed world; therefore, in all probability, Ester experienced derealisation due to altered perceptions of her

realities. I interpreted Ester's rendition of her breast cancer diagnoses to be in keeping with her experiences of depersonalization and derealization, which often are the result of traumatic life events.

6.4.3 'A memoir written in flesh': Ester's experience of treatment

Ester's breast cancer treatment trajectory affected her on a physical, emotional, psychological and social level. As mentioned before, Ester had two mastectomies done, followed by two different breast reconstructive surgical procedures. Ester reported that both mastectomies were performed with "military" precision and without complications. She disclosed a different experience regarding her reconstructive surgeries. A TRAM flap was performed on her right breast, and a Latissimus dorsi flap was recommended for her left breast (see Appendix F). Ester reported: "My—the two breasts looked completely different, the breast (left) basically collapsed."

My, die twee borste lyk baie verskillend die bors het amper soos
heeltemal platgeval.

I recollected from my experience as a registered nursing sister, especially working in an operating theater and post-operative ward, that breast reconstructive surgeries could be experienced as a physical onslaught and often added to the maiming of the female body. I deduced from Ester's accounts that she endured multiple physical invasions. In addition, the scarring on her back and abdominal areas became constant reminders of her loss of femininity, her altered appearance and her loss of body integrity and identity. Ester reported: "But afterward I thought, it is not that important to me now, that my breast looked right, even though what I saw in the mirror was not a beautiful face. But to me, life was more important at the time than to struggle in and out of the hospital with my breast."

Maar ek het toe agterna het ek gedink vir my is dit nie so belangrik nou, my bors laat dit nou moet reg lyk nie, alhoewel dit was nie 'n mooi gesig toe ek in die spieël kyk nie. Maar vir my was my lewe op daai tyd meer belangrik as om nou te sukkel in en uit hospitaal met 'n bors.

At the same time that Ester received her first breast cancer diagnosis and treatment schedule, her sister's husband passed away, as mentioned before. I thought this incident had a profound effect on Ester's perspective of her illness. As previously disclosed, Ester's notion about the life-changing effects of breast cancer probably led her to discern the unpredictability of life and the certainty of death. I discerned that the death of her sister's husband underscored Ester's perceptions about her own life and own mortality, hence her statement: "life at that time was more important." In reference to her sister's loss, Ester disclosed: I lost part of my body, but what weighs more?"

Ek het 'n deel van my liggaam verloor, maar wat weeg swaarder?

My interpretation was that Ester came to realize the importance of life and of being alive. She chose to live through this breast cancer experience even though she feared the illness trajectory, the complications and side effects of cancer treatment. Ester described her uncertainty regarding the mastectomy: "I just could not picture myself without a breast. I was very conscious about it."

Ek kon my net nie indink hoe dit gaan lyk nie. Ek was baie bewus daarvan.

Making these choices regarding surgery and treatment interventions probably enhanced her sense of agency and, therefore, her sense of personal identity. However, regardless of this enhanced sense of personal identity, Ester disclosed feeling apprehensive about her body identity, including her physical appearance, body integrity, and body image.

I perceived Ester as a woman who invested in her physical appearance and considered it to be an important element of her attractiveness and, therefore, her body identity. From Ester's account, I concluded that she felt self-conscious about her body. She reported: "I am, I always was, if Harold (husband) maybe wants to hold me, then I would always put my hands in front of my breasts."

Ek is, ek was altyd, as Harold (pseudonym) my miskien vashou of so dan sal ek altyd my hande...Jou hande voor jou borste...

Ester probably experienced shame and awkwardness. Her self-consciousness pertaining to her physical appearance and body integrity might have impeded on her relationship with her husband and, even more so, restricted her overall functioning, well-being and, therefore, her sense of personal identity. I concluded from Ester's account that she experienced low self-esteem, which included low self-worth, self-efficacy, and authenticity. She probably perceived this altered version of herself as flawed, imperfect and lacking sexuality and femininity. Ester reported: "Because if you look at the media, I mean it is, a woman must look so and so. It took me a while before I...or when I got dressed I would turn..."

Want as jy miskien na die media kyk en so, ek meen dit is, die vrou moet so en so, en so lyk. Dit het vir my 'n tydjie gevat voordat ek miskien nou weer--, of as ek aangetrek het dan sal ek altyd draai."

I agreed with Ester in the matter of the objectification of the female breast as a superior symbol of female sexuality. In our culture, breasts are the personification of femininity, motherhood, nurturance, and attractiveness. For Ester, the matter of physical appearance and body identity were further complicated by her experiences of chemotherapy and radiation. Ester described her side effects: "And I was terrible, my face was, I just was, let me say I felt unattractive because my face was swollen...my face

always turned blood red on the second day...And I felt ill; I could not lift my head from the pillow...My skin became dark from the radiation...My hair fell out in patches...[sic]"

En ek het verskriklik, my gesig was, ek het net so, laat ek sê onaantreklik gevoel want my gesig was so opgeswel...ek het bloedrooi altyd in my gesig geword, die tweede dag...En siek gevoel het en kan my kop nie oplig van die kussing af en so nie... My vel het baie donker geword van die bestraling...Hare het kol kol uitgeval.

Ester's description of her treatment side effects led me to conclude that she experienced agony, which included extreme physical and emotional suffering. Ester, in all likelihood, experienced loss of sense of agency, loss of conscious identity and, ultimately, a loss of sense of personal identity. These experiences were probably emphasized when financial constraints prompted her to consider further consultations for her breast cancer at a government hospital.

Ester received most of her treatment interventions in private hospitals and reported her first encounter at the government hospital as a "culture shock." Ester's account was as follows: "But when I got to the ward, aaah, I thought, please Dear Jesus I do...I know there are good doctors here but it was like a culture shock for me, it was a huge—my almost fear...But then I thought I need to make a mind shift, and I said I am here to be helped and I should not look at the other things [sic]".

Maar, toe ek nou daar onder in die saal kom, aaah, toe dink ek asseblief Liewe Jesus ek wil (onduidelik). Ek weet hier's goeie dokters maar seker maar net, dit was 'n, vir my soos 'n culture shock, dit was nou 'n groot... my amper vrees...Maar toe dink miskien moet ek nou net 'n mind shift maak en sê ek is nou hier om gehelp te word en ek moet maar nou nie die ander goed nou raaksien nie."

Ester spoke about a “culture shock” when comparing her experiences in private healthcare to government healthcare services. Ester probably referred to the unknown physical surroundings, as well as feelings of distress, anxiety, resentment and fear, bewilderment, rejection, and deprivation when she spoke about a “culture shock.” She spoke about her experience in terms of her aptness of “making a mind shift.” Ester regained a sense of agency, which included her perspective on assistance. She probably realized that she had limited options regarding future treatment expectations.

I concluded that the limited options and, in her mind, inexorable circumstances presumably gave rise to anticipatory grief, which circumscribed her emotional pain and perceptions of multiple losses such as loss of body identity, beliefs, and personal identity. All circumstances considered, Ester possibly also experienced complicated grief with regard to her multiple cancer diagnoses. From Ester’s detailed descriptions of her experiences, I inferred that Ester’s life was dominated by the psychological, emotional, social and physical aspects associated with breast cancer, which unquestionably resulted in the loss of sense of personal identity.

6.4.4 ‘Living death or dying life’: Ester’s meaning-making

Ester’s meaning-making practices, from my interpretation, were, and still are, multifaceted and complex, taking into account her past and present experiences throughout her illness trajectory since 1998. Coping with multiple diagnoses of cancer dominated Ester’s existence and were of crucial importance in relation to her meaning-making. Ester acknowledged the fact that, despite assistance from various support structures, coping and meaning-making was primarily her responsibility. Ester reported: “At the end of the day *you* have to get through it.”

Aan die einde van die dag moet jy daardeur kom.

I explicated that Ester realized her own role as the principal agent in her own life and meaning-making efforts. I am of the understanding that acknowledgment is an important factor of acceptance, which is pivotal to meaning-making. Ester reported that at times she felt like objecting to treatment: “Sometimes you felt, oh Father (Lord) do I have to go again, and there were days, I can remember, I cried continuously, but I could not put my finger on it, what the reason was. It seemed like the tears would not stop [sic]”.

Partykeer het jy gevoel, ag Vader moet ek nou weer gaan, en daar was dae, kan ek onthou, wat ek net gehuil het maar ek kon nooit my vinger daarop sit wat is dit nie. Dit lyk die trane kan net nie ophou nie.

Ester reported feelings of non-acceptance and rebuttal at times; she also described her emotional pain and overwhelm. From my interpretation, Ester has been subjected to a relentless battle against breast cancer (and other cancers), which comprised numerous losses. Her “continuous crying” could have been part of her bereavement in which she was grieving for her loss of personal identity. Ester also spoke about her anger: “ You are angry, why me?

Jy’s kwaad, hoekom ek.

Ester’s questioning attitude and her anger was possibly part of her grieving process but also part of her acceptance. Ester was searching for reason and meaning for her breast cancer experiences, which reflected her existential plight of cancer. She had to adjust to uncertainties and an unpredictable life, which doubtless impacted on her meaning-making practices.

Keeping in mind that Ester had been living with breast cancer, as well as other cancers for the past 19 years, she was probably compelled to change her perspectives of her world as well as her sense of personal identity. Ester disclosed: “I think as you get older you see things

from a different perspective, things that were less important when you were younger now become more important.”

Ek dink as jy ouer word dan sien jy ook miskien dinge in ‘n ander perspektief of so, goed wat miskien vir jou minder belangrik was toe jy jonger was, raak vir jou meer belangrik

In all probability, Ester had countless opportunities to reflect on her life and meaning-making of her breast cancer. I concluded that Ester’s reflections led to mindfulness and an awareness of the present moment. Ester reported: “And I think one must take your day, your life on a daily basis and tell yourself that today you are going to this and that [sic].”

En ek dink ‘n mens moet net jou dag, jou lewe op ‘n daaglikse basis vat en miskien jou sê vandag wil ek dit doen en dit doen.

My interpretation is that mindful living is an imperative part of meaning-making and acceptance, self-worth and, therefore, sense of personal identity. Ester was also mindful of the support from her daughter, husband, family, and friends. Ester disclosed: “I do not know how a person gets through this thing without other people, I mean my family was my cornerstone.”

Ek weet nie hoe ‘n mens sonder ander mense deur hierdie ding kom nie, ek meen my familie was my steunpilaar.

I deduced that Ester found meaning through the unconditional acceptance from her family and more specifically, from her daughter. I concluded that Ester’s social support included emotional, psychological and physical support from her daughter and husband. She probably would not have survived her cancers without the support. Ester reported having a

special relationship with her daughter: “We were always very close, and I think, yes, maybe this (breast cancer) strengthened that bond.”

Ons twee was maar altyd baie na aan mekaar, en ek dink dit net, ja miskien daai bond net nog sterker gemaak.

Ester’s relationship with her daughter clearly gave meaning to her experiences. From Ester’s accounts, I deduced that her daughter, from an early age, adopted a nurturing role, seeing to her physical needs as well as her emotional needs. Ester reported: “From when she (daughter) was little, I can remember how she remembered the Bactroban (ointment), she remembered everything because she used to unpack the little things and she helped me .”

Van kleins af het ek onthou hoe sy altyd kon onthou bactroban, onthou sy baie goed want sy’t al die goedjies altyd so uitgepak en vir my gehelp.

Ester described a change in roles and identity, which possibly led to the disruption of their family functioning. Her daughter assumed responsibility, and from Ester’s accounts, it was clear that her daughter also experienced psychological distress. Ester reported: “She (daughter) was also very worried, almost as if she was angry with me because I am sick.”

En sy was ook baie bekommerd. Amper partykeer so half kwaad vir my omdat ek siek is. [patient emotional]

Upon disclosing this information, Ester became emotional; from my perspective, these events, and the quality of her relationship with her daughter were meaningful to Ester and contributed greatly to her meaning-making efforts. Ester made meaning through self-transcendence, as well as spiritual transcendence. She accounted: “And I prayed the whole time. I had to believe, and there were many prayers that went up [sic].”

En ek het net heeltyd gebid. Ek ons moet net vertrou en daar's so baie gebede wat opgaan.

Ester might have experienced thoughts of doubt and as result feelings of shame. She reported an expectation of belief, because of the “many prayers.” These prayers prompted Ester to live in the present and to be mindful of her happiness. When I asked Ester about her future expectations, she reported: “ I should live every day as if it is my last day and that I would be happy, and I am thankful for every day I see the sunrise.”

Ek elke dag sal leef asof dit my laaste is en dat ek net gelukkig sal wees, ek is net dankbaar vir elke dag wat ek weer die son kan sien opkom.

I concluded that Ester accepted her breast cancer experiences. She gained an altered conscious identity and regained her autobiographical identity, her belief, her sense of agency, a different social identity and finally, her (new) personal identity.

6.5 Conclusion

This enduring illness experience had, and still has, an overwhelming experiential and physical impact on Ester. Breast cancer diagnosis and treatment did not only affect Ester; her family also endured the psychological, emotional and social implications of this illness. I concluded that despite the traumatic experience of breast cancer, Ester made meaning of this experience and found a sense of purpose. The following chapter, Chapter 7, consists of a discussion of the three case studies: focusing on similarities within the differences, as well as the differences within similar experiences.

CHAPTER 7

DISCUSSION

7.1 Introduction

The aim of this study was to explore and interpretatively understand the subjective experiences of breast cancer diagnosis and treatment from the first-person perspective. Chapter 7 provides a structured, detailed, subjective and individually analyzed discussion of the findings from the qualitative data presented in Chapters 4, 5 and 6.

Findings from three cases studies will be discussed in view of existing literature with regard to four identified psychological concepts as described Chapter 2. I shall first provide a section on case study reflections. Following is a discussion of the four concepts, which includes perceptions of breast cancer, experiences of breast cancer diagnosis, experiences of breast cancer treatment and meaning-making and coping. In keeping with the presentation of this study as three case studies, the discussion of each concept includes individual descriptions as per case study, followed by a comprehensive deliberation (inferences) concerning similarities and differences found in experiences reported. This proposed outline for the discussion is congruent with case study research guidelines (Pietkiewicz & Smith, 2014; Salkind, 2010; Smith et al., 2009).

7.2 Case study reflections

A detailed case study can be ternary in worth. First, comprehensive information and knowledge are generated regarding a particular individual and situation-specific responses (Salkind, 2010; Smith & Eatough, 2007; Smith, 2017). Secondly, analysis of a case study allows the researcher to consider associations between different aspects of that specific narrative (Smith & Eatough, 2007). Thirdly, and in keeping with Warnock's perspective on shared humanity, in-depth exploration of an individual's unique account (detail) take us closer

to important features of the general (Salkind, 2010; Smith & Eatough, 2007; Smith et al., 2009).

Treating each participant as an individual case study enabled me to emphasize idiographic experiential details (Biggerstaf & Thompson, 2008). Of equal importance, the process allowed elicitation of “the gem, a singular utterance made by a participant with great resonance across the case and corpus” (Smith, 2017. p. 303).

7.3 Perceptions of breast cancer

The impact of perceptions of breast cancer on women’s experiences with regard to diagnosis and treatment has as yet been fairly adequately established in the literature review, Chapter 2. Lily, Mina, and Ester reported different perceptions of breast cancer. Undisputedly, these perceptions have been influenced by their personal beliefs, knowledge, and expectations of health and illness, as well as their sociocultural backgrounds (Donnelly et al., 2013; Inan et al., 2016; Wilson, 2016). Important to note that they also reported similarities within their perceptions, which were reflective of Warnock’s perspective of shared humanity (Smith et al., 2009).

Lily: Lily’s constructed knowledge and perception pertaining to breast cancer was deeply established in prior enforced and unavoidable encounters, namely her mother’s perception of breast cancer. This finding is congruent with perspectives in the literature on beliefs (relatively stable structure of our knowledge) where present and future interpretations of events and experiences are dependent on prior (already existing) knowledge (Kubie, 2014; Sotala, 2010).

Contrived circumstances required Lily to assume the role of caregiver. Lily reported negative recollections and assertively rejected connectivity to her mother. This finding is compatible with previous research conducted by Gadoua (2011). She reported on the long-term

negative impact of parentification. In Lily's context, the continuous exposure to her mother's thanatophobia, as well as her mother's helpless and hopeless approach to her illness, left Lily with a sense of futility and decreased self-validation. Therefore, I surmised that her perception of her own breast cancer was biased, laden with negativity, denial, and avoidance.

The process of denial and avoidance was underscored by Lily's use of the word, "it" in reference to breast cancer and also by her blunt refusal to have regular breast examinations done. This finding seems to be contradictory to research conducted by Rayne and colleagues (2017), in which they reported findings of positivity towards a medical cure. However, Ramathuba and colleagues (2015), as well as Mosavel and colleagues reported similar findings. These studies mentioned were conducted in South Africa.

Lily's account of her initial thoughts of breast cancer (not her own) included trauma, fatalism, mortality, psychological distress, uncertainties, cognitive stagnation, and fears. Lily feared possible losses (mother dying) but she also intensely feared breast cancer. These findings were consistent with existing research conducted by Krombein and DeVilliers (2006). They reported that even though the majority of participants were knowledgeable about lumps and cancer, fear of being diagnosed seemed to countermand sound decisions regarding health.

Mina: In fact, Mina initially reported that she had no knowledge of breast cancer prior to her own experience. Reporting (perceived) lack of knowledge was significant in the context of her sociocultural background. This was supported by Kleinman's Explanatory Model of Health, which recognizes that individual perspectives have to be interpreted with cognizance of specific sociocultural backgrounds (Donnelly et al., 2013; Inan et al., 2016; Lee, 2015).

With regard to knowledge, Obikunle (2016) and Muthoni and Miller (2010) reported similar findings pertaining to lack of knowledge and level of education. In addition, Obikunle (2016) reported findings on communication skills, which was complemented by the following finding in this present study. Describing breast cancer as "deep" and comparing cancer with a

“small plant that roots itself” reflected Mina’s perception of breast cancer. Mina’s use of colloquial language was of great significance in the interpretation of her experiences. Colloquial language, as used in this case study, reflected the intensity of Mina’s emotions and feelings, as well as the magnitude of this experience for her.

Mina’s perception of her breast cancer was also greatly influenced by her fatalistic approach to this illness and life in general. Mina perceived cancer to be equal to suffering and death. This finding was compatible with results reported by Mosavel and colleagues (2010) pertaining to cancer perceptions of South African mothers and daughters. In Mina’s context, fatalism was (is) essential for her survival. Fatalism is indicative of having an external locus of control, which in the context of this study released Mina of personal responsibility towards making life-changing decisions.

This finding is in keeping with South African research conducted by Ramathuba and colleagues (2015), as well as international studies (Al-Azri et al., 2014). Notwithstanding considerable efforts and prominent research perspectives on patient education, it is fascinating that findings from this present study also indicated the prevalence of a fatalistic life perspective, negative attitudes and reluctant admittance to the possibility of breast cancer (Lee, 2015; Krombein & De Villiers, 2006; Ramathuba et al., 2015; Salant et al., 2006).

Ester: Ester’s initial perception of breast cancer was one of indifference. Breast cancer happened to other people. Ester never considered herself to become a victim, much less a survivor and moreover, a sufferer of chronic illness.

The extant literature reviewed often referred to lack of knowledge, but I concluded that, in the context of Ester’s experience, it was not a matter of (lack of) knowledge; rather it was a matter of oblivion. Lee (2015) reported findings pertaining to breast cancer perceptions where women believed that no symptoms meant no illness. Ester, however, did not even consider the

possibility of breast cancer, much fewer symptoms. This finding is therefore partially contradictory to findings from extant research.

Ester's reported perception of breast cancer equaled mortality, and I concluded that she experienced anxiety and fear related to this possibility. This finding is in keeping with various extant research (Al-Azri et al., 2014; Inan et al., 2016; Ohaeri et al., 2012; Olsen, 2016).

According to Ester she "did not fit the profile." She was young (40 years old), maintaining a healthy lifestyle, no family history, therefore, a low-risk candidate. Ester's account was compatible with findings from a study conducted by Muthoni and Miller (2010), where they reported on lifestyle- and other factors as probable causes of breast cancer.

Inferences: Lily, Mina, and Ester each had a personal perception of breast cancer.

Lily's perception of breast cancer was shaped by parental influences, which contributed greatly to her avoidance of her own breast cancer. Mina's perception was significantly impacted by her (perceived) lack of knowledge, which probably supported her fatalistic approach to her illness. Ester's initial perception of breast cancer highlighted her indifference to this illness. This generated a state of oblivion, which ultimately led to extreme psychological distress.

In view of their different perceptions, Lily, Mina and Ester also shared similarities. The following similar features were identified, namely thoughts of death and dying, questions regarding mortality, initial non-acceptance, cognitive suppression and emotional trauma. All three participants had difficulties rendering the word breast cancer. This could have been part of their experiential avoidance of the illness. Inan and colleagues (2016) reported similar findings of dissent. These findings (descriptions) are in keeping with the principles of the theoretical framework, Constructivism. Lily, Mina, and Ester constructed their own personal realities, interpretations, and perceptions of breast cancer.

7.4 Subjective experiences of breast cancer diagnosis and treatment

7.4.1 Breast cancer diagnosis

The lived experience of breast cancer diagnosis, as expressed by Lily, Mina and Ester were affected by their perceptions as rooted in their personal beliefs and attitudes (Mermer et al., 2016). A breast cancer diagnosis is still synonymous with dying (Al-Azri et al., 2014; Inan et al., 2016; Olsen, 2016). This finding was also accurate for the participants of this present study, irrespective of the level of education and access to sufficient knowledge. Olson (2016) described breast cancer diagnosis as the pivotal moment in which a woman's reality as known to her irrevocably changes. This finding was only true for two of the participants of this study (Mina and Ester). Lily reported a different experience. The next sections will discuss Lily's, Mina's and Ester's individual and particular findings pertaining to breast cancer diagnosis.

Lily: A salient feature of Lily's diagnosis experience was her extreme denial and experiential avoidance. Notwithstanding her family history of breast cancer, Lily reported her non-acceptance of breast cancer. According to the extant literature on breast cancer diagnosis (Gullatte et al., 2010; Jones et al., 2010; Watson, Greer, Blake, & Shrapnell, 2006), denial, avoidance and delaying treatment, by and of itself, are expected and accepted behavior. However, in Lily's case, her behavior not only reflected denial and avoidance. She maintained this behavior, as well as non-adherence to regular breast examinations, and moreover, refusal of medical advice for years.

This was an interesting and unique finding, especially in view of Lily's family history. Her deliberate unwillingness to accept and adjust to a possibility of breast cancer resulted in destructive behavior with pathological consequences. None of the reviewed literature disclosed a similar finding. Lily's motivation for *not* seeking help was supported by intrinsic thoughts and feelings, as well as extrinsic events (Nugent, 2013). Ultimately, in Lily's context, a breast

cancer diagnosis would indicate personal failure (becoming her mother), a degraded self-concept and loss of personal identity.

Receiving a diagnosis of breast cancer, typically, elicits emotional challenges, emotional adjustment difficulties and extensive negative psychological consequences (Beatty et al., 2008; Strauss, 2014). The finding with regard to Lily's experience of receiving her diagnosis was as controversial as it was incongruent with existing literature. Lily delivered her own diagnosis, expressing the actual words even before the doctor did. Instead of being assisted, Lily comforted the doctor. In Lily's context, her behavior was indicative of the importance of personal identity, and more so, sense of agency ('I can change the world in certain ways'), autobiographical identity ('I am the person living the narrative of my life') and conscious identity ('I am the author of my subjective experience') (Kubie, 2014). This finding reported is unique and similar findings were not found in the extant literature.

Lily reported suppression of thoughts regarding breast cancer. In Lily's context, I concluded this suppression to be a self-protective strategy, as well as a form of experiential avoidance. This finding was consistent with results from a quantitative study on expressive suppression and cognitive reappraisal (Moore, Zoellner & Mollenholt, 2008).

Lily's account revealed a radical change of her identity, pre-breast cancer as opposed to post-breast cancer. Lily experienced feelings of diminished self-worth, loss of self-esteem and confidence and adopted an attitude of apathy. Therefore I concluded that Lily experienced her diagnosis of breast cancer as a transformative process, which, for her, encompassed a series of existential events (disrupted regular practices, abilities and expectations) and extreme loss of personal identity. Lily's account was in keeping with reports from comprehensive literature reviews (Carel, 2016; Ng et al., 2017).

Mina: Noticeable features in Mina's account of her experience of her breast cancer diagnosis were first, her frequent diminution of the illness, secondly, her profound

metaphorical expression pertaining to her experience and thirdly, her intrinsic religiosity and absolute surrender. Mina's reported emotions and feelings of fear and shame were in keeping with existing research on breast cancer diagnosis (Liamputtong & Suwankhong, 2016; Ohaeri et al., 2012; Strauss, 2014).

Interestingly though, was Mina's "fearful embarrassment" pertaining to her (perceived) lack of knowledge. Findings and results regarding (lack of) knowledge, as well as feeling of shame and fear, have been reported extensively (Lee, 2015; Rayne et al., 2017; Ramathuba et al., 2015), but findings pertaining to being fearfully embarrassed and experiencing guilt, for not knowing "what a growth was" (lack of knowledge) were not found in the literature reviewed. I conclude that this finding is probably not exclusive but has not been highlighted as in this current study. Reasons for alleged lack of knowledge should be investigated as part of research regarding breast cancer diagnosis.

As mentioned, Mina frequently used diminutive descriptions in reference to breast cancer, namely "the little lumps," "small test," "a little bit of a cancer." The use of diminutives is commonly associated with child-directed speech, terms of endearment, lover- and pet-directed speech, expressing smallness, non-serious informal situations and positive rather than negative emotions (Dabašinskienė, 2009). Evidently, my conversation (interview) with Mina did not adhere to these features. For that reason I found Mina's conversational style, especially in view of the seriousness of her illness-situation, to be telling of her attitude towards breast cancer.

Mina's narration was a mitigation of her breast cancer. Mina attempted to minimise the severity of a life-threatening diagnosis in an effort to make this experience more bearable. In Mina's context, the use of diminutives was a functional expression of her diagnosis experience (Allen et al., 2016; Dabašinskienė, 2009). I concluded that Mina deliberately used diminutives was an unknown manner to reduce the psychological distance between us, as strangers, in the

interview, but more so to communicate her emotions of fear, shame, and anxiety (Dabašinskienė, 2009). Similar findings have not been reported in the literature reviewed. I, therefore, concluded that a unique in-depth finding such as this is the result of case study IPA. This is in keeping with findings as revealed by Smith (2011, 2017), explaining the importance of a “single utterance” (p.303).

Mina used a profound and unconventional metaphorical expression in reference to her diagnosis experience. She described her experience, the moment she received her diagnosis, as similar to the physical pain of giving birth. From all reports, Mina experienced emotional turmoil, disappointment and was in a state of shock. These findings were consistent with existent research (Ganz, 2008; Ristevski et al., 2014; Schmid Büchi et al., 2008). However, Mina’s metaphorical expression is unique and has not been reported elsewhere in the literature review. This is, as also mentioned above, in keeping with “the gem” as explained in section 7.2 (Smith, 2017).

I concluded Mina’s detailed and vivid description of her diagnosis experience as remarkable given the fact that she was diagnosed with breast cancer (bilateral) in 2011. This finding was congruent with findings and results from existing research regarding the extremity of a breast cancer diagnosis experience (Bloom et al., 2012; Iwatani et al., 2013, LeBlanc & Kamal, 2017, Mitchel, 2014; Knobf, 2015). Moreover, the finding supports research regarding the intense sense of loss of personal identity that is part of receiving a diagnosis (Carel, 2016; Kubie, 2014; Nugent, 2013; Price Herndl, 2006).

Another significant aspect of Mina’s experience of her diagnosis was her absolute surrender and religiosity, both intrinsic and extrinsic. Her fatalistic approach was not exclusive to her diagnosis experience but noticeable throughout her illness trajectory. In line with previous studies that investigated religiosity and spirituality, a predominant finding of this study was Mina’s internalization of the Bible’s teachings, as seen in her literal quotation of

Psalm 23 (Gall et al., 2005; Pargament, 1997; Wilson, 2016; Xu, 2016). Religious beliefs and spirituality have been described as a form of avoidance, but despite scientific and psychological animosity spirituality has been reported effective as a way of coping in times of difficulty (Gall et al., 2005; Pargament, 1997, Wilson, 2016). Argorastos, Demiralay, and Huber (2014) reported on the positive effects of prayer and scripture reading. This is congruent with Mina's reports on religious beliefs and spirituality.

Ester: Ester gave an emotional description (she became tearful) of the time when she received her *first* diagnosis. She reported extreme psychological distress. More important, she also reported transient global amnesia, which was probably caused by the overwhelming emotions. She disclosed a state of shock and disbelief, all of which are affiliated with stressful life events. Researchers have reported similar findings and results in the past (Ganz, 2008; LeBlanc & Kamal, 2017; Mitchell, 2014; Ohaeri et al., 2012; Sheppard et al., 2014).

Breast cancer diagnosis led Ester to question her own mortality and sense of personal identity. She experienced an existential plight, transformation and entered a liminal space. This finding is in keeping with extant research on mortality and identity (Carel, 2016; Inan et al., 2016; Kernan & Lepore, 2009; Koutri & Avdi, 2016).

In view of this findings, the question arose in my mind: How did Ester eventually perceive herself: as a victim of cancer, a survivor of breast cancer or a sufferer from chronic illness? I concluded that Ester's initial beliefs upon both her breast cancer diagnoses were contradictory to the quoted statement from the National Cancer Institute (2009, as cited in Waldrop, O.Conner, & Trabold, 2011): "In cancer, a person is considered to be a survivor from the time of diagnosis until the end of life" (p.451). Inceptively, Ester did not consider herself a victim (sufferer), much less a survivor of breast cancer.

With this in mind, Ester's breast cancer trajectory was interspersed with psychological distress, uncertainties, oscillating between illness and health, dying and well-being. This

finding is in keeping with reports from previous studies (Aaronson et al., 2014; Ganz, 2008; Holland, 2004; Ohaeri et al., 2012; Olsen, 2016; Waite et al., 2015). Ester was challenged with an existential crisis, which left her questioning the very foundations of her life and her sense of personal identity. Price Herndl (2006) highlighted the existential crises often faced by breast cancer patients with the clearly stated question posed by this patient group “Who am I now?” (p. 222).

Breast cancer diagnosis disrupted Ester’s autobiographical identity, body identity, sense of agency, social identity, beliefs and conscious identity (Kubie, 2014). The disruption influenced her physical and cognitive capacities, hampering adjustments, which ultimately impacted on her personal identity. This finding was in keeping with findings from the literature reviewed (Carel, 2016; Oyserman et al., 2012; Price Herndl 2006; Wolf, 2015).

Inferences: Lily, Mina, and Ester revealed unique and personal experiences regarding breast cancer diagnosis. A similar diagnosis with shared characteristics, different experiences and moreover, different levels of involvement and participation. Lily, Mina, and Ester reported a form of avoidance and denial. These reports denial and avoidance reflect Warnock’s idea of shared humanity (Smith et al., 2009). Furthermore, these reports indicate the differences within similar experiences. Lily revealed pathological experiential avoidance of receiving a diagnosis, whereas Mina’s absolute surrender could be interpreted as a form of avoidance. Ester’s oblivion towards breast cancer and more so, herself as a victim of breast cancer could be reflective of her denial and avoidance.

Mina and Ester recounted experiences of psychological distress, whilst Lily’s behavior and approach were unpredictable and unconventional, in view of existing literature. The latter highlighted the importance of the (humanistic) value of narratives in understanding cancer from a first-person perspective (Naidu, 2012). Irrespective of reported differences, all three participants clearly remember (in detail) the moment they received the diagnosis. They also

revealed that to have been a pivotal moment in which their realities, known and unknown, changed forever.

This finding was also reported in previous research (Olsen, 2016; Price Herdl, 2006; Schweitzer et al., 2012; Sherman et al., 2012). However, the intensity of the moment for each individual could be captured, and only partially so, by means of in-depth conversation and rapport (Naidu, 2012; Smith et al., 2009). I conclude that a diagnosis of breast cancer results in identity disruption also called biographical disruption. A breast cancer diagnosis experience is a personal encounter shared by many but experienced individually.

7.4.2 Breast cancer treatment

Breast cancer treatment and treatment-related side effects embody a transformative experience consisting of physical, psychological and emotional aspects (Bates, Taub & West, 2016). Lily had a unilateral mastectomy, and Mina and Ester both had bi-lateral mastectomies. Although they shared similar treatment interventions, namely surgery, chemotherapy, radiation and medication, their experiences of the treatment interventions were dissimilar in various ways.

Existing research demonstrates the significant influence of visual representations of breast cancer treatment, which undoubtedly result in psychological and social challenges (Al-Azri et al., 2014; McCann et al., 2010; Ogden & Lindridge, 2008; Pidlyskyj et al., 2014).

Lily: Lily's report of her treatment experience was conveyed by means of two rich comparisons. She compared her breast cancer treatment to being held captive in a Jewish concentration camp. She also compared her experiences of treatment-related side effects to "being like a dead man." She probably envisioned herself a prisoner, being held captive by a disease from which there was no escape. This finding, pertaining to a 'sense of captivity' has not been described in the literature reviewed. This metaphor was laden with meaning.

Lily's disclosed experiences included subjective feelings of terror, fear, anxiety, frustration, rage, hopelessness, despair and more importantly, dissociation from her breast and recurrent nightmares. These intense reactions are not dissimilar to those seen in individuals suffering from post-traumatic stress syndrome (PTSD) (Carll, 2007). An in-depth discussion of PTSD is not within the scope of this thesis but unquestionably warrant further research. This finding is particular to Lily and has not been described in the previous literature reviewed on breast cancer.

In reference to the treatment, she often included herself in the patient group, talking in the third person instead of first person. Existing research has shown that third-person self-talk could reduce mental anguish, enhance emotional regulation and broaden the psychological distance from stressful experiences. In addition, it is a relatively uncomplicated form of self-control (Moser & Henion, 2017). Lily's efforts of avoidance in order to maintain some kind of sense of agency were in keeping with findings from Moser and Henion's (2017) study.

Important to note, Lily received her treatment at a government hospital. Lily's disclosures regarding treatment interventions included psychological experiences such as fear ("scared"), a sense of insecurity and uncertainties, loss of control, humiliation, loss of dignity and demoralization, as well as mortality. She also reported (perceived) lack of information, which could have been partly cause and/or result of her psychological distress. This finding, regarding extreme psychological distress and negative emotional experiences, is congruent with exciting research (Fu et al., 2008; Lindwall & Bergbom, 2009; Love et al., 2015; Whitehead & Hearn, 2015).

Lily's accounts regarding her physical experience of treatment highlighted her fear of losing her breast. Even though she reported feeling anxious regarding the surgery, in actuality she intensely feared the inevitability of her circumstances. She experienced anticipatory grief in anticipation of the physical loss and moreover, the potential losses that such a physical invasion

embodied. Findings regarding fear, anxiety, death, and dying have been extensively reported in previous research (Naidu, 2012; Sarenmalm et al., 2009; Sherman et al., 2012; Thewes et al., 2015). However, the specific finding regarding anticipatory grief is particular to Lily's experience and therefore only partially congruent with results reported in previous research as discussed in the review.

In addition, Lily's disfigured body became the constant reminder of all the losses she suffered. These losses included loss of personal identity (all components) (Kubie, 2014), loss of femininity, loss of motherhood, loss of time, loss of occupation, loss of belief, loss of dignity and loss of respect and recognition. Her emotional and psychological experiences were probably a direct result of her specific physical complications. This finding was supported by research conducted previously (Ganz, 2008; Ristevski et al., 2014; Schmid Büchi et al., 2008).

Lily's account of her treatment experience in a government hospital, specifically in the ward prior to and following surgery, revealed experiences of dehumanization, lack of respect and demoralization, as well as feeling incapacitated. In view of successful treatment outcomes and personal healing, these descriptions were disconcerting and warranted further investigation. Findings pertaining to experiences in hospitals have not been exclusively reported in the research reviewed for the purpose of this study. Largely, Lily's reported experiences of treatment and treatment-related side effects were congruent with extant literature as described in Chapter 2 (Aaronson et al., 2014; Adler & Page, 2008; Braybrooke et al., 2015; Ganz, 2015; Pidlyskyj et al., 2014; Schmid Büchi et al., 2008).

Mina: The most salient features in Mina's report regarding her treatment were the uncertainties regarding her physical appearance and fear of bodily changes (loss of breasts, hair loss, weight loss, sunken eyes, blurred vision). She experienced an intense sense of deprivation and depreciation pertaining to her femininity. She reported, "Without breasts..., it makes me feel like a man." Existing research seems to emphasize this change in self-concept, including

loss of body integrity (Beatty et al., 2008; Oyserman et al., 2012). However, similar intense descriptions of loss of body identity had not been reported in the research reviewed.

In keeping with findings from studies conducted earlier, Mina's self-concept and therefore her approach to treatment and side effects were constructed within her socio-cultural background (Breakwell, 2010; Glynn, 2006; Lipps, 2006). Mina's distress regarding acceptance from her child and her community, as well as the responses from "the outside-people, resulted in decidedly antisocial behavior. In a review regarding cultural factors, Lee (2015) reported similar findings. However, as a result of the cultural influences, Mina employed self-imposed social isolation. Social isolation was described as a known reaction to challenges associated with breast cancer (Al-Azri et al., 2014; Banning, 2014; Kaptein et al., 2015). The finding from this study regarding Mina's social isolation was compatible with extant research. I concluded Mina's isolation to be partly a symptom of her deficient adjustment. Hawthorne (2008) reported that social isolation could be telling of mental health issues such as depression, social anxiety and abandonment fears (social rejection). Social isolation could also enhance feelings of shame and low self-worth. In view of this literature, the finding from this study is therefore congruent with Hawthorne's (2008) findings.

Mina's account of receiving treatment in a government hospital revealed her apprehension. Interestingly, Mina's apprehension was caused by a lack of privacy. Being in close proximity to (sick) strangers provoked anxiety and Mina reported she felt exposed, fearful and vulnerable. This finding is particular to Mina. Existing research propose opposite findings, rather, patients find solace in sharing their experiences (Sarenmalm et al., 2009; Sherman et al., 2012). I concluded Mina's behavior to be in keeping with her self-imposed social isolation.

In addition, Mina described her post-surgery experience in terms of death and dying. She also refused any further treatment. I concluded, that contrary to her fatalistic approach, Mina was, in fact, fearful of dying. Existing research report extensively on fatalism, death and

dying, but no findings were reported on possible contradictory statements pertaining to mortality as was revealed in Mina's case (Aaronson et al., 2014; Ganz, 2008; Gullate et al., 2010; Holland, 2004; Ohaeri et al., 2012). This kind of finding, therefore, could only be possible through in-depth one-on-one conversations when patients are encouraged to talk about themselves and their particular experiences (Naidu, 2012). Mina's maimed body became a constant reminder of her loss of body identity, sense of agency, conscious identity and ultimately an altered sense of personal identity.

Ester: An important feature in Ester's report regarding treatment pertained to her personal identity, which was to a great extent situated in her body identity, physical appearance, and body integrity. Ester's initial breast cancer surgeries challenged her body identity and her sense of body integrity. This finding was also reported in previous research (Kubie, 2014, Lindwall & Bergbom, 2009; Moreira et al., 2010). In an effort (sense of agency) to ameliorate her abhorred circumstances at the time, Ester opted for reconstructive surgery. The main purpose of the reconstructive surgery was to improve her appearance (beautify). Rather, Ester experienced an unexpected and unpredicted physical onslaught. Ester experienced self-estrangement; her scarred and maimed physical body portrayed a stranger. Ester disclosed being self-conscious and shameful about her appearance and changed body. This finding was supported by research conducted by Lindwall and Bergbom (2009) and Moreira and colleagues (2010).

Undoubtedly, Ester experienced identity disruption, psychological distress, and moreover body change stress. According to Frierson and Anderson (2006), body change stress symptoms are similar to traumatic-like stress symptoms. Ester demonstrated similar symptoms namely, recurrent recollections of events, avoidance, and loss of interest in activities and intimacy, as well as anger and frustration (Frierson & Anderson, 2006; Wolf, 2015).

Ester's account regarding treatment (chemotherapy and radiation) and treatment-related side effects included all of the physical aspects as reported in the literature review, section 2.7 (Bates et al., 2016; Janz et al., 2007; Love, 2015; Pilkington et al., 2015; Winch et al., 2015). The finding was therefore congruent with existing research. Ester's report regarding her treatment experience at a government hospital included descriptive words such as "culture shock" and "huge fear." Ester's previous treatments, including the surgeries, were done at private hospitals. Comparing treatment circumstances, Ester experienced feelings of distress, anxiety, resentment and fear, bewilderment, limited options, rejection, and deprivation.

All circumstances considered, Ester experienced anticipatory grief, which reflected her emotional pain and perceptions of multiple losses such as loss of body identity, beliefs, and personal identity. Similar findings were reported regarding anticipatory grief (Overton & Cottone, 2016; Strauss, 2014). In addition, Ester possibly also experienced complicated grief with regard to her multiple cancer diagnoses. Ester reported intense grief that impacted on her daily functioning.

She also disclosed a persistent longing and sadness, as well as a continuous sense of disbelief and inability to accept the agonizing truth of living with breast cancer. This finding pertaining to grief (anticipatory and complicated) and breast cancer had not been explained in such depth in the literature reviewed. The finding was however supported by findings from a case study with regard to complicated grief, conducted by Shear (2015). Further research regarding a possible association and interconnection between breast cancer and PTSD (traumatic-like symptoms) should reveal interesting findings, which will ultimately influence health care interventions and outcomes. In conclusion, resulting from numerous treatment interventions, Ester's mutilated body was (still is) a constant reminder of her (perceived) loss of femininity, her altered appearance and her loss of bodily integrity and personal identity.

Inferences: It is evident that Lily, Mina, and Ester experienced emotional and physical turmoil pertaining to breast cancer treatment and more so, treatment in a government hospital. All three participants reported on the complexity of treatment, which includes the combinations of treatment interventions and procedures, a number of medical visits, waiting times, multiple care providers, copious decision-making and information overload (Ganz, 2008).

In contrast to both Lily's and Ester's experiences of treatment and treatment-related side effects, Mina showed uncanny (unearthly) resilience. The question arose as to whether Mina's experience was causally or consequently related to her intrinsic religiosity. Both Lily and Ester reported spirituality to only become important following their breast cancer diagnosis and treatment, irrespective of the way they were brought up. This finding warrants further research regarding the correlation between coping (meaning making) and spirituality in living with breast cancer.

Both Lily and Ester displayed traumatic symptoms, more so Lily than Ester, whilst Mina did not report traumatic symptoms to the same extent. However, all three participants reflected on how the losses and the consequences of the perceived losses of living with breast cancer affected their life as a whole. This was in keeping with previous findings (Carel, 2016; Larson, 2009). In view of research conducted by Smith and Rhodes (2014) each of the participants in this study reported a loss, which represented a major part of their life, something especially valuable and irreplaceable.

In keeping with the idiographic commitment of this study, Lily's report regarding treatment experience's emphasized a sense of captivity, whilst Mina's intense uncertainties reflected her paradoxical fatalistic approach. Ester's unpredicted experience from health to illness indicated her critical and life-changing conditions and decisions that facilitated complete transition and adjustment. These findings were partially supported by extant research (Carel, 2016; Larson, 2009; Schulzke, 2011).

As reported in the literature review, Chapter 2, treatment interventions highlight intricacies in a woman's relationship with her body, her gender, sexuality and identity (Naidu, 2012). Therefore, as part of Warnock's shared humanity, treatment interventions and experiences reflect an intrusion, disconnection, and disturbance of the sense of identity (Koutri & Avdi, 2016; Smith et al., 2009). Losing a breast is equivalent to various losses of critical values including loss of sense of belonging and loss of personal identity (Begovic-Juhant, 2012; Naidu, 2012; Sarenmalm et al., 2009).

7.5 Meaning-making and coping

It was evident from the three different accounts that a diagnosis and treatment of breast cancer change a woman's perspective on life, her attitude to life and her way of living (Cipora et al., 2017; Drageset et al., 2015; Sarenmalm et al., 2009). Even though meaning making and coping was not the main focus of this study, it was critical to the discussion of the subjective experiences of women receiving breast cancer diagnosis and treatment.

Following is a short discussion of the main aspects associated with Lily's, Mina's and Ester's meaning-making and coping. It was evident that meaning-making and coping were personal experiences (Drageset et al., 2015; Kaptein et al., 2015; Kim et al., 2010; Marlow et al., 2003; Waldrop et al., 2011).

Lily: Lily's meaning-making and coping were paradoxical in nature. Even though Lily conveyed an attitude of acceptance and positivity, she was adamant that she has no future prospective beyond six months. Lily admitted that acceptance of breast cancer was "an enormous battle." According to existing research, acceptance is a critical aspect of meaning-making (Cipora et al., 2017; Liamputtong & Suwankhong, 2016; Mermer et al., 2016; Stanton et al., 2015). Acceptance is considered a time of decisive change (Liamputtong & Suwankhong, 2016).

Lily constructed the meaning of her breast cancer experience on her own terms, by living in the moment and through self-transcendence (living for her daughter). Lily never completely accepted her breast cancer. Therefore her meaning-making was incomplete. In view of this, the finding from this study was only partially compatible with existing findings (Liamputtong & Suwankhong, 2016; Matthews & Cook, 2009; Messerly, 2017). In addition, this finding was in keeping with Lily's reported experiential avoidance.

Interestingly, Lily never reported seeking explanations for her breast cancer. She did, however, report blame towards her mother. This reflects an external locus of control. Therefore, Lily's meaning-making was influenced by circumstantial factors, managing factors, and socio-economic factors. This finding was similar to results from extant research (Drageset et al., 2015; Khalili et al., 2013; Kvillemo & Bränström, 2014).

Spiritual transcendence was only employed at a later stage. Experiencing a life-threatening illness, breast cancer, prompted Lily to consider a different perspective. She also made meaning through self-transcendence. Living for (and through) her daughter and husband enhanced Lily's self-validation, sense of agency and personal identity. This finding was supported by existing research (Liamputtong & Suwankhong, 2016; Wong, 2016). I concluded that Lily only partially made meaning of her breast cancer experience.

Mina: Mina adopted a fatalistic perspective and approach. Her primary strategy to understand and make meaning was, and still is, by means of spiritual transcendence, religiosity, and self-transcendence, as well as finding plausible explanations. Mina did not find convincing evidence, despite efforts to gain knowledge from doctors. She opted for complete surrender to God, as part of her meaning-making and coping. This finding was in keeping with existing research pertaining to spirituality, culture, history, language and social interactions (Donnelly et al., 2013; Elias et al., 2015; Khalili et al., 2013; Liamputtong & Suwankhong, 2016; Mehrabi et al., 2015; Quest, 2014; Sabado et al., 2010; Wilson, 2016).

Mina reported experiences of intense emotional pain, surrender, self-transcendence (living for her granddaughter), metamorphosis, love, compassion, forgiveness, appreciation, and humility. This finding was congruent with Pargament's (2015) report on the language of spirituality. In addition, as part of Mina's attempts to make meaning, she questioned and attributed breast cancer causality to "God's will." This finding is similar to results from extant studies (Gullatte et al., 2012; Leak et al., 2008; Muthoni & Miller, 2010; Obikunle, 2016; Swinton et al., 2011). I concluded that Mina accepted her breast cancer and was able to find meaning in her experience.

Ester: Coping with multiple diagnoses of cancer dominated Ester's existence. Ester acknowledged the fact that, despite assistance from various support structures, namely family, friends and colleagues, coping and meaning-making was primarily her responsibility. This reflected an internal locus of control, which in the context of Ester's life enhanced meaning-making and coping.

Ester's initial reaction regarding her being the victim of breast cancer reflected her disbelief. Kernan and Lepore (2009) refer to this incongruity as "psychological discord" (p.1177). The finding from Ester's study is similar to research previously conducted (Kernan & Lepore, 2009; Liamputtong & Suwankhong, 2016).

As part of her meaning-making, Ester investigated possible causal explanations such as lifestyle choices and risk factors. According to the literature reviewed, researchers reported similar findings (Apffelstaedt, 2016; Apffelstaedt & Baatjes, 2007; Derman et al., 2009). Ester did not, however, find solace in these explanations, which impeded on her acceptance and ultimately, her meaning-making.

Ester also reported bereavement (depression, anxiety, anger), which extended beyond the criteria for adjustment. In view of this finding, I concluded Ester experience as a transformation. This transformative experience surpassed physical and mental dysfunction,

resulting in the disintegration of meaning structures and quality of life. Researchers have reported similar findings in the past (Carel, 2016; Mehrabi et al., 2015; Ng et al., 2017).

All of these factors mentioned led Ester to reevaluate the significance of her life. As a result and an important aspect in Ester's meaning-making was self-transcendence, which was evident (and still is) in her relationship with her daughter. She also reported mindful living and spiritual transcendence, which was imperative in her meaning-making and acceptance.

Mindfulness as a term encompasses awareness, caution, enlightenment, and sensitivity, as well as a remembrance (Carlson, 2016; Carlson & Halifax, 2011). Mindfulness is an approach, described by Bartley (2017) as an intimate way of being gentle and kind, whilst reflecting on internalized struggles. This finding was in keeping with previous research as mentioned.

Ester's accounts pertaining to spiritual transcendence included (lack of) expectations of belief, "many prayers" from friends and family, thoughts of doubt and feelings of shame for her lack of conviction. This finding regarding spiritual conviction was contradictory to a finding from Rayne and colleagues (2017). I concluded that Ester's acceptance of her breast cancer was never complete, but she succeeded in comprehending her breast cancer experience.

Inferences: Breast cancer is often perceived as synonymous with death (Al-Azri et al., 2014; Inan et al., 2016; Mosavel et al., 2010; Naidu, 2012; Olsen, 2016). Following the initial bewilderment and confusion, most women attempt to manage and accept their changed realities. This finding reported by Liamputtong and Suwankhong (2016) was partially in accordance with the findings for Lily, Mina, and Ester. The three participants reported different experiences within a similar situation of meaning-making. Lily and Ester's acceptance of their breast cancer was incomplete, whereas Mina unconditionally accepted breast cancer as part of God's plan for her life.

Lily, Mina, and Ester reported on the personal intensity of the breast cancer experience. Their narratives on breast cancer included the following shared processes, namely existential

plight, transformative experience and liminality (Carel, 2016; Inan et al., 2016; Kernan & Lepore, 2009; Koutri & Avdi, 2016). Lily, Mina, and Ester considered the moment they received their diagnosis to have been the pivotal moment in which their known realities were irrevocably altered (Olsen, 2016; Price Herdl, 2006; Schweitzer et al., 2012; Sherman et al., 2012).

With regard to spiritual transcendence (surrender) and religion as part of meaning-making, Lily, Mina, and Ester reported different experiences. Mina lived in absolute surrender whilst Lily, and Ester demonstrated a lesser degree of religious adherence. However, Lily, Mina, and Ester revealed the significance of self-transcendence as a part of their meaning-making. All three women established meaning in living for their children. An interesting observation, Lily, and Ester each have one daughter, and Mina has a granddaughter, living with them. All three daughters accepted the role of caregiver and nurture. The paucity of research regarding mother-daughter relationships, more so role reversal, in breast cancer warrants further exploration of this finding.

In summary, meaning making in breast cancer happened within a context of a life in peril, thereby forcing Lily, Mina and Ester to reappraise their life-world and processes of meaning-making and coping (Lindwall & Bergbom, 2009; Sarenmalm et al., 2009). Breast cancer, meaning-making, and coping practices are, however, multi-faceted personal, as well as complicated social constructed concepts.

7.6 Conclusion

Chapter 7 provided a discussion of the research findings of three case studies in relation to existing literature reviewed in Chapter 2. According to Finlay (2008), “However rich and comprehensive, any one analysis is, inevitably, incomplete, partial, tentative, emergent, open and uncertain” (p. 6). I acknowledge that each participant (case study) justify a significantly

greater profundity than was possible in this discussion. However, concordant with the idiographic commitment of the phenomenological descriptions, Lily, Mina and Ester disclosed subjective (personal) experiences of breast cancer that would not have been revealed and discussed otherwise.

CHAPTER 8

CONCLUSION, LIMITATIONS AND RECOMMENDATIONS

8.1 Introduction

Chapter 8 provides a comprehensive conclusion of the research presented in the study regarding the subjective experiences of three South African women, Lily, Mina, and Ester, receiving diagnoses and treatment at a public health breast clinic. The chapter also provides insight into possible limitations of the study and recommendations with regard to future research.

8.2 Conclusion

With this study, I attempted to explore, describe, and interpretively understand the lived psychosocial experiences of individual breast cancer patients receiving diagnosis and treatment from a first-person perspective. This qualitative IPA study adopted a case study design using a phenomenological research approach. The analysis of each of the selected three case studies led to the emergence of a single overarching psychological concept of what it means to live with breast cancer, namely loss of personal identity. The findings across the three case studies revealed similarities within different experiences, as well as differences in similar experiences.

Existing literature reviewed regarding experiences associated with breast cancer diagnosis and treatment was substantial, but in-depth findings pertaining to the lived experiences of individual women living with breast cancer were limited. Worldwide patients' views and experiences are considered fundamental in the assessment of healthcare systems (Tsianakas et al., 2012). The reported subjective experiences of Lily, Mina, and Ester, made valuable contributions to phenomenological breast cancer research in South Africa.

First, accounts from Lily, Mina and Ester revealed differences in breast cancer diagnosis acceptance trajectories. In view of health care provision, these differences were significant in comprehending their psychological adjustment to breast cancer diagnosis (Windell et al., 2015). In summary, these narratives included thoughts of mortality, extreme psychological distress, and loss of personal identity. More importantly, these revelations highlighted the devastating consequences of lack of readily available psychosocial support as part of multidisciplinary routine care in public breast clinics. I concluded that the availability of a psychologist, or designated health care worker, would undoubtedly have alleviated, to some extent, the stressful cognitive impact upon receiving breast cancer diagnoses.

Secondly, Lily, Mina, and Ester disclosed valuable information pertaining to treatment intervention experiences, as well as management of treatment-related side effects, at a government hospital. In summary, these reported experiences consisted of feelings of indignity, mortification, demoralization and undeniably, loss of personal identity. As with diagnosis experiences, I surmised that these feelings could have been diminished with the availability of a psychologist or designated health care worker, providing much needed psychosocial support.

Disclosure of these personal (and particular) experiences emphasized the importance of seeing the person in and behind the patient. Acknowledging Lily, Mina, and Ester as experts of their own experiences, encouraging them to be active partners in the decision making regarding their treatment interventions would, in my interpretation, have enhanced their recovery and treatment outcomes. Consequently, the narratives of Lily, Mina, and Ester pertaining to their subjective experiences of breast cancer diagnosis and treatment contribute to the paucity of phenomenological research, as is currently the situation in South Africa.

These explanatory narratives could benefit the improvement of informed and appropriate and more importantly, customized health care interventions. In addition, these narratives could facilitate policy development for South African women, and their families,

living with breast cancer. Therefore, this study constitutes an important part in qualitative breast cancer research in South Africa.

8.3 Limitations

The following limitations were identified, namely researcher bias and participant subjectivity, sample selection, language translation and research design. These will be discussed separately in the next paragraphs.

Researcher bias: According to Anderson (2010), the degree of excellence of qualitative research is determined by the researcher's competence, as well as the researcher's personal bias and peculiarities. I strived, at all times, to be cognizant of my own personal experiences, my socio-cultural background and the personal psychological impact of this study (Anderson, 2010; Visser, 2017) in order to establish and maintain research rigor.

Participant subjectivity: Participants in this study were regarded as experts of their personal breast cancer experiences. This approach could account for a blurred circumscription of the researcher-participant positioning and could have presented as a possible limitation. In keeping with data collected on participants' perceptions of breast cancer, their preconceived beliefs regarding research expectations and breast cancer experiences could have impacted the research and should therefore be mentioned as a possible limitation (Anderson, 2010; Barber, 2016; Doumit, 2017).

Sample selection: The sample selection for the present study consisted of three women, all of whom attended the Breast Clinic at Tygerberg Hospital. In keeping with the flexible principles of IPA, which suggest a small number of participants, selection of participants was by means of purposive sampling. Possible limitations related to purposive sampling are selection bias, researcher judgment errors and diminished trustworthiness (Dudovskiy, 2016). In the context of the present study, purposive sampling has proven effective in exploring

subjective breast cancer experiences, capturing both similarities and differences, as well as associated meanings (Dudovskiy, 2016; Palinkas et al., 2015), even though the sample might not have been representative of the broader patient population.

Language translation: The primary language used in the present study, to conduct and analyze interviews, was Afrikaans. In the process of translation, the meaning is reconfigured (Roth, 2013). Translation includes speaking, thinking, reading and transcription, all of which were significant aspects in this study (Roth, 2013). For the very reason that this study's main concern was the exploration and interpretation of what it means to receive a breast cancer diagnosis and treatment, I concluded that translation could have been a possible limitation. In an effort to minimize loss of depth of meaning I provided both the original Afrikaans excerpt and the English translation of the specific excerpt.

Research design: The present study was performed at a single point in time, therefore the study could only report findings related to that specific moment. This could be interpreted as a possible limitation. Given a different time frame, the study would have probably generated different outcomes and features (Doumit et al., 2017). Even though replication of the exact findings would prove onerous, the findings generated from this study were well founded and justifiable.

8.4 Recommendations

The present study generated promising findings. These findings provided in-depth knowledge into what it means to live with breast cancer. The paucity of existing South African research on this subject prompted the initiation of this study. Taken into account the rising incidence of breast cancer and breast cancer-related deaths in South Africa, as well as limited psychosocial support and poor socioeconomic circumstances, there is merit in expanding the scope of this research.

Women attending the Breast Clinic at Tygerberg Hospital are but a fraction of South African women receiving breast cancer diagnoses and treatment. Therefore inclusivity is strongly recommended for future research. In the context of breast cancer research, inclusivity refer to first, women (patients) attending different breast cancer clinics (private and public) across South Africa, secondly, breast cancer patients who might otherwise be marginalized such as disabled (physical and learning) women, as well as racial and sexual minorities and thirdly, breast cancer in men.

A further recommendation would include expanding the breadth and width of this subject matter to include neglected aspects associated with breast cancer as discovered in the context of this study. These aspects include first, perceptions of breast cancer, secondly, subjective experiences upon discovery of a breast lump, thirdly, subjective experiences related to the waiting period between discovery (of lump) and receiving a diagnosis, fourthly, the association between breast cancer and disorders such as Post Traumatic Stress Syndrome and Obsessive-Compulsive disorder, fifthly, subjective experiences of clinician-patient communication and the effect (positive and negative) on treatment outcomes, sixthly, subjective experiences pertaining to follow-up consultations and lastly, the role of spirituality in breast cancer meaning-making.

All of these subjective experiences, as mentioned above, greatly impact on the breast cancer illness trajectory. Professional health care providers' (clinicians and hospital personnel) limited knowledge and understanding of particular subjective experiences ultimately influence participant co-operation, or lack thereof, as well as the prolonged duration of treatment and less successful health outcomes.

In keeping with the principles of breadth and width, the following recommendation would be further case study research. With case study research patients' narratives are situated within the larger cancer health care system (Naidu, 2012). Moreover case study research

highlights the humanistic value of patients' narratives, especially with reference to comprehending the lived experiences of breast cancer (Naidu, 2012). Finally, I agree with Smith's (2017) recommendation regarding the employment of in-depth, detailed IPA studies as complementary to the larger reconnaissance of quantitative psychology.

8.5 Concluding remarks

This present study strongly asserted the importance of qualitative phenomenological research of subjective experiences of breast cancer as they pertain to perceptions of breast cancer, breast cancer diagnosis experiences, breast cancer treatment experiences and meaning-making.

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APPENDICES

Appendix A

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT: Psychosocial aspects of breast cancer

REFERENCE NUMBER:

PRINCIPAL INVESTIGATOR: Professor SA Kagee

CO-INVESTIGATOR: Ms. R. Roomaney

ADDRESS: Psychology Department, Wilcox Building, Ryneveld Street, Stellenbosch, 7600

CONTACT NUMBER: 0218083442 / 0218083973

You are being invited to participate in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the researcher or staff at the healthcare facility where you found this information leaflet any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the Health Research Ethics Committee at Stellenbosch University and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

The focus of the proposed study is on the psychological and social experiences that women have when they receive a diagnosis of breast cancer and undergo treatment. We have identified certain emotional and psychological salient issues that affect the psychosocial well-being and quality of life among breast cancer patients. These will be the focus of the interview in which you will take part.

The research project will be conducted at Breast Clinic in the Division of Radiation Oncology at Stellenbosch University and Tygerberg Hospital. If you agree to participate, you will be asked to participate in a confidential interview as part of the study. The interview will be conducted by a trained research assistant and will be audio recorded. The interview will take between 30 and 60 minutes to complete. All information will be confidential.

Who may participate in this study?

In order to participate in the study you should be able to speak and understand English well enough to allow for informed consent and be interviewed. Interviews may also be conducted in Afrikaans, should you wish to do so. You also need to be diagnosed with breast cancer and be receiving treatment at the breast clinic. Patients diagnosed with any other serious acute or chronic illness may not participate in the study. You should be 18 years or older in order to participate.

Will you benefit from taking part in this research?

There are no direct benefits associated with participating in this study.

Are there in risks involved in your taking part in this research?

There are no known risks to participating in this study. Should you have any concerns do not hesitate to contact the researcher. Should you feel distressed during the interview, please inform the interviewer who will refer you to a counselling centre. If you feel distressed after the interview then please contact the numbers for support given below.

Who will have access to your medical records?

The researchers will have access to your medical records. Cancer-specific information will be obtained from chart notes and consultation with the oncology staff. This information will include staging of cancer, date of diagnosis, occurrence and date of detected metastases and recurrences, treatment plan, current treatment stage, prognosis and medication prescription across the course of treatment.

This study is being conducted independently of the healthcare facility through which you are recruited and does not in any way affect your ongoing treatment at the facility. All information collected will remain confidential. Only the researchers will have direct access to the data. All persons handling data will be required to sign confidentiality agreements. Any information that may lead to the identification of participants will be removed when disseminating the research. The Stellenbosch University researchers will be working with a researcher at the Free University of Berlin, Professor Nina Knoll. In the event that data from this study will be shared with Professor Knoll, all names and identifying information will be removed.

Will you be paid to take part in this study and are there any costs involved?

You will not be paid to take part in the study.

Is there anything else that you should know or do?

- If you feel distressed please contact our counselling centre (Welgavallen) at 0218082944 or the Trauma Centre for Survivors of Violence and Torture at 0214657373
- If you would like more information about this study please contact the Principal Investigator (Prof. Kagee) at 0218083442 or Co-investigator (Ms. Roomaney) at 0218083973.
- You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by your study doctor.
- You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I agree to take part in a research study entitled (*insert title of study*).

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.

- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) on (*date*) 2015.

.....

Signature of participant

.....

Signature of witness

Declaration by investigator

I (*name*) declare that:

- I explained the information in this document to
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use a interpreter. (*If a interpreter is used then the interpreter must sign the declaration below.*)

Signed at (*place*) on (*date*) 2015.

.....

Signature of investigator

.....

Signature of witness

Consent to confirm diagnosis

I hereby grant permission to the researchers to contact my doctor/nurse to obtain information from my medical records.

Signature of patient.....

Appendix B

Participant demographic and medical information

<i>Participant demographic and medical information</i>								
Pseudonym	Age	Year of Diagnosis	Stage of Breast Cancer	Other Cancer	Family History	Chemo	Radiation	Mastectomy Single/Double/Lumpectomy
Lily	50	2011	Stage 4	Unknown	Mother	Yes	Yes	Single – Right
Mina	54	2011	Stage 2	Unknown	Unknown	Yes	Yes	Double
Ester	58	1998 2005	Stage 1 - R Stage 1 - L	Ribcage Lung Spine	Mother	Yes	Yes (Multiple)	Single – Right Single – Left (Double)

Appendix C

Experiences of breast cancer patients at the Tygerberg Breast clinic.

Interview schedule

I am going to ask you a few questions about your experience with breast cancer. Please take your time to answer the questions, providing as much or as little information as you feel comfortable sharing. The information that you share will be treated as confidential. If at any time you would like to end this interview you are free to do so.

A. Diagnosis

1. Can you tell me about your experience with breast cancer?
2. Can you tell me about your diagnosis?
3. What were the events that lead up to your diagnosis?
4. What was your experience with doctors and the health care system when you received the diagnosis?
5. Describe the support available to you after receiving the diagnosis?
6. How do you decide on who you choose to share your diagnosis with?
7. What concerns do you have about disclosing your breast cancer to others?

B. Treatment

8. Can you tell me about your treatment?
9. How do you feel about the treatment that you receive?
10. What is your experience with doctors and the health care system while receiving treatment?
11. Why do you choose to continue treatment at the breast clinic?
12. How do you cope with cancer and the medical treatment?
13. Describe the support available to you while and after receiving treatment?

C. Psychosocial experiences

14. How does cancer affect you psychologically or emotionally?
15. Can you tell me how your body has changed since being diagnosed with cancer? How do you feel about these changes?
16. How does cancer impact your personal relationships?
17. Can you tell me how cancer affects your quality of life?
18. How do you make sense of your breast cancer experience?
19. What have you learned about yourself through this experience?

Bylaag C

Ervaringe van borskanker pasiënte betrokke by die Borskliniek, Tygerberg.

Onderhoud skedule

Ek gaan 'n paar vrae vra rakende jou/u ervaring met borskanker. Neem asseblief genoeg tyd om die vrae te beantwoord, en gee slegs die hoeveelheid inligting waarmee u gemaklik is. Alle inligting sal vertroulik hanteer word. U is welkom om enige tyd die gesprek te eindig.

A. Diagnose

1. Kan u/jy my vertel van u/jou ervaring met borskanker?
2. Kan u/jy my vertel van u/jou diagnose?
3. Kan u/jy my vertel van gebeure wat aanleiding gegee het tot u/jou diagnose?
4. Hoe /wat was u/jou ervaring met dokters en die gesondheidsorg sisteem toe u/jy gediagnoseer is?
5. Beskryf asseblief die beskikbare ondersteuning aan u/jou nadat u/jy gediagnoseer is?
6. Hoe het u/jy besluit met wie u/jy die diagnose sal/wil bespreek?
7. Wat is u/jou bekommernis rakende die bekendmaking van u/jou diagnose aan ander?

B. Behandeling

1. Kan u/jy my vertel van u/jou behandeling?
2. Hoe voel u/jy oor die behandeling wat u/jy ontvang?
3. Hoe ervaar u/jy die dokters en die gesondheidsorg sisteem tydens u/jou behandeling?
4. Hoekom verkies u/jy om vol te hou met behandeling by die Borskliniek?
5. Hoe hanteer u/jy kanker en die mediese behandeling?
6. Beskryf asseblief die ondersteuning wat tot u/jou beskikking is tydens en na afloop van behandeling?

C. Psigososiale ervarings

1. Hoe beïnvloed kanker u/jou emosioneel of sielkundig?
2. Kan u/jy my vertel hoe u/jou liggaam verander het sedert u/jy gediagnoseer is met kanker? Hoe voel u/jy oor hierdie veranderinge?
3. Wat is die invloed van kanker op u/jou persoonlike verhoudings?
4. Kan u/jy my vertel hoe kanker u/jou kwaliteit van lewe beïnvloed?
5. Hoe maak u/jy sin van u/jou borskanker ervaring?
6. Wat het die ervaring van borskanker u/jou geleer van uself/jouself?

Appendix D

Approval Notice by the Health Research Ethics Committee.

Approved with Stipulations Response to Deferral

04-Dec-2015

Kagee, Shaheen SA

Ethics Reference #: N15/08/077

Title: Psychosocial aspects of breast cancer treatment.

Dear Prof Shaheen Kagee,

The Response to Deferral - (*New Application*) received on 03-Nov-2015, was reviewed by Health Research Ethics Committee 1 via Committee Review procedures on 03-Dec-2015.

Please note the following information about your approved research protocol:

Protocol Approval Period: 03-Dec-2015 -02-Dec-2016

Present Committee Members:

Abulfathi, Ahmed AA

Els, Petrus PJJS

Ferris, William WF

Hall, David DR

Hoek, Kim KGP

Kearns, Elaine E

Lachman, Anusha A

Philander, Cynthia C

Potgieter, Sunita S

Rohland, Elvira EL

Weber, Franklin CFS

Welzel, Tyson T

Werely, Cedric CJ

The Stipulations of your ethics approval are as follows:

Kindly note that when data is shared with another institution there should be an agreement in place to protect your intellectual property rights.

Please remember to use your **protocol number (N15/08/077)** on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review:

Please note a template of the progress report is obtainable on www.sun.ac.za/rds and should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Translation of the consent document to the language applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372
Institutional Review Board (IRB) Number: IRB0005239

The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health (healthres@pgwc.gov.za Tel: +27 21 483 9907) and Dr Helene Visser at City Health (Helene.Visser@capetown.gov.za Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.
For standard HREC forms and documents please visit: www.sun.ac.za/rds

If you have any questions or need further assistance, please contact the HREC office at 0219389657.

Included Documents:

Budget
Interview schedule 2
Duke functional social support questionnaire
Application form_signature page
Declaration N Knoll
Demographic information
FACT_B Version 4
Declaration J Githaiga
Flyer
Hopkins symptom checklist
CV N Knoll
Center for Epidemiologic Studies Depression Scale
Medical Information extraction form
20151103 DEF Protocol
20151103 DEF Consent quantitative study
CV R Roomaney
CV S Kagee
Interview schedule 4
Checklist
CV J Githaiga
Declaration R Roomaney
Patient questionnaire
Protocol
Payment exemption request
Benefit finding scale for breast cancer
Article - brief cope
Consent form quantitative study
Brief pain inventory
20151103 DEF Consent qualitative study
Brief illness perception questionnaire
Application form
Breast cancer therapy adherence questionnaire
20151103 DEF Cover letter
Breast impact of treatment scale
Questionnaire
Declaration S Kagee

Interview schedule 3
Consent form qualitative study
Interview schedule 1
Protocol Synopsis

Sincerely,
Franklin Weber
HREC Coordinator
Health Research Ethics Committee 1

Investigator Responsibilities

Protection of Human Research Participants

Some of the responsibilities investigators have when conducting research involving human participants are listed below:

1. Conducting the Research. You are responsible for making sure that the research is conducted according to the HREC approved research protocol. You are also responsible for the actions of all your co-investigators and research staff involved with this research.

2. Participant Enrolment. You may not recruit or enrol participants prior to the HREC approval date or after the expiration date of HREC approval. All recruitment materials for any form of media must be approved by the HREC prior to their use. If you need to recruit more participants than was noted in your HREC approval letter, you must submit an amendment requesting an increase in the number of participants.

3. Informed Consent. You are responsible for obtaining and documenting effective informed consent using only the HREC-approved consent documents, and for ensuring that no human participants are involved in research prior to obtaining their informed consent. Please give all participants copies of the signed informed consent documents. Keep the originals in your secured research files for at least fifteen (15) years.

4. Continuing Review. The HREC must review and approve all HREC-approved research protocols at intervals appropriate to the degree of risk but not less than once per year. There is no grace period. Prior to the date on which the HREC approval of the research expires, it is your responsibility to submit the continuing review report in a timely fashion to ensure a lapse in HREC approval does not occur. If HREC approval of your research lapses, you must stop new participant enrolment, and contact the HREC office immediately.

5. Amendments and Changes. If you wish to amend or change any aspect of your research (such as research design, interventions or procedures, number of participants, participant population, informed consent document, instruments, surveys or recruiting material), you must submit the amendment to the HREC for review using the current Amendment Form. You may not initiate any amendments or changes to your research without first obtaining written HREC review and approval. The only exception is when it is necessary to eliminate apparent immediate hazards to participants and the HREC should be immediately informed of this necessity.

6. Adverse or Unanticipated Events. Any serious adverse events, participant complaints, and all unanticipated problems that involve risks to participants or others, as well as any research-related injuries, occurring at this institution or at other performance sites must be reported to the HREC within five (5) days of discovery of the incident. You must also report any instances of serious or continuing problems, or non-compliance with the HREC's requirements for protecting human research participants. The only exception to this policy is that the death of a research participant must be reported in accordance with the Stellenbosch University Health Research Ethics Committee Standard Operating Procedures www.sun025.sun.ac.za/portal/page/portal/Health_Sciences/English/Centres%20and%20Institutions/Research_Development_Support/Ethics/Application_package All reportable events should be submitted to the HREC using the Serious Adverse Event Report Form.

7. Research Record Keeping. You must keep the following research-related records, at a minimum, in a secure location for a minimum of fifteen years: the HREC approved research protocol and all amendments; all informed consent documents; recruiting materials; continuing review reports; adverse or unanticipated events; and all correspondence from the HREC

8. Reports to the MCC and Sponsor. When you submit the required annual report to the MCC or you submit required reports to your sponsor, you must provide a copy of that report to the HREC. You may submit the report at the time of continuing HREC review.

9. Provision of Emergency Medical Care. When a physician provides emergency medical care to a participant without prior HREC review and approval, to the extent permitted by law, such activities will not be recognised as research nor will the data obtained by any such activities should it be used in support of research.

10. Final reports. When you have completed (no further participant enrolment, interactions, interventions or data analysis) or stopped work on your research, you must submit a Final Report to the HREC.

11. On-Site Evaluations, MCC Inspections, or Audits. If you are notified that your research will be reviewed or audited by the MCC, the sponsor, any other external agency or any internal group, you must inform the HREC immediately of the impending audit/evaluation.

Appendix E

Approval Notice by the Western Cape Government.



TYGERBERG HOSPITAL
REFERENCE: Research Projects
ENQUIRIES: Dr GG Marinus
TELEPHONE: 021 938 5752

Ethics Reference: N15/08/077

TITLE: Psychosocial aspects of breast cancer treatment.

Dear Prof Shaheen Kagee

PERMISSION TO CONDUCT YOUR RESEARCH AT TYGERBERG HOSPITAL.

In accordance with the Provincial Research Policy and Tygerberg Hospital Notice No 40/2009, permission is hereby granted for you to conduct the above-mentioned research here at Tygerberg Hospital.

A handwritten signature in black ink, appearing to be "D Erasmus", written over a horizontal line.

**DR D ERASMUS
CHIEF EXECUTIVE OFFICE**

Date: 25 February 2016

Administration Building, Francie van Zijl Avenue, Parow, 7500
tel: +27 21 938-6267 fax: +27 21 938-4890

Private Bag X3, Tygerberg, 7505
www.capegateway.gov.za

Appendix F

ESTER'S RECONSTRUCTION SURGERIES:

TRAM flap

“During TRAM flap surgery, an incision is made along your bikini line and an oval section of skin, fat, blood vessels, and muscle is taken from the lower half of your belly, moved up to your chest, and formed into a breast shape.

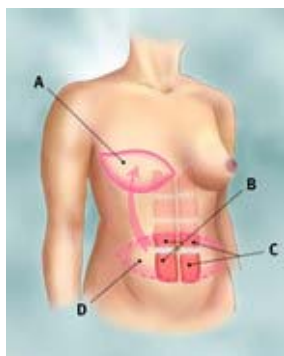
If you're having a muscle-sparing free TRAM flap, less muscle should be moved than if you're having a traditional free TRAM flap or a pedicled TRAM flap. Make sure you understand clearly how much of the abdominal muscle is going to be used. For either of the free TRAM flaps, the tiny blood vessels that feed the tissue of your new breast are matched to blood vessels in your chest and carefully reattached under a microscope.

For a pedicled TRAM flap, the section of skin, fat, and muscle is slid through a tunnel under the skin up to your chest. The blood vessels of the pedicled TRAM flap are left attached to their original blood supply in your abdomen.” (Breastcncer.org, 2015)

Retrieved from:

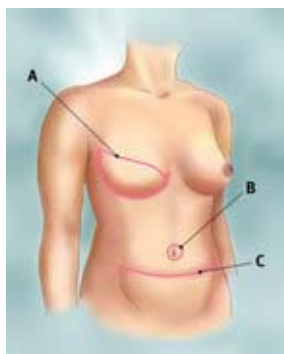
<http://www.breastcancer.org/treatment/surgery/reconstruction/types/autologous/tram/what-to-expect>

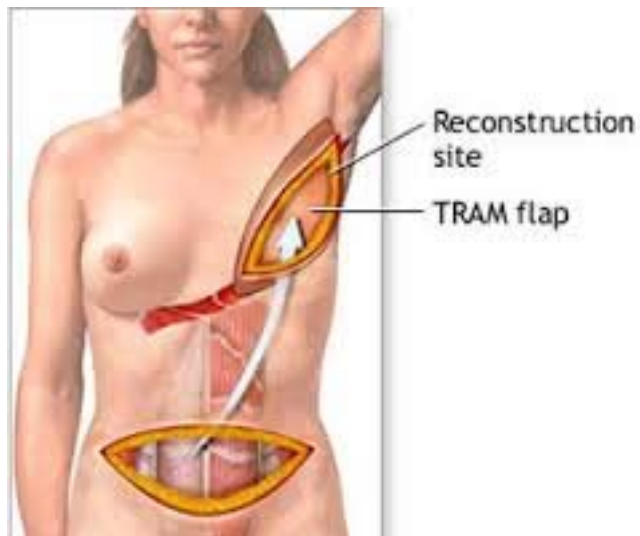
TRAM Reconstruction



A Mastectomy site **B** Right trans rectus abdominis muscle **C** Left trans rectus abdominis muscle **D** Oval section of skin, fat, and muscle that will be used to recreate the breast

Either free TRAM flap procedure lasts about 6 to 8 hours.



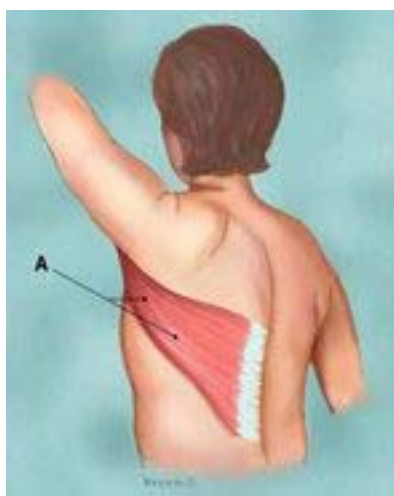


DORSI flap

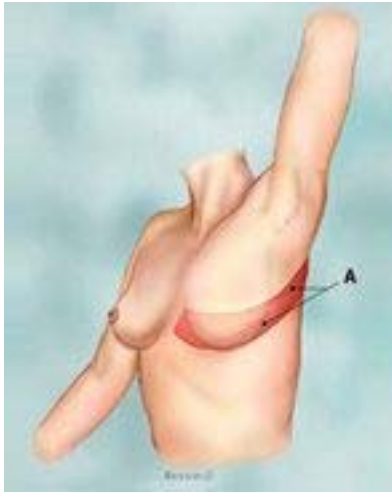
“During latissimus dorsi flap reconstruction surgery, an incision is made in your back near your shoulder blade. Then, an oval section of skin, fat, blood vessels, and muscle is slid through a tunnel under the skin under your arm to your chest and formed into a breast shape. The blood vessels are left attached to their original blood supply in your back. If any blood vessels do have to be cut, they are matched to blood vessels in your chest and carefully reattached under a microscope.” (breastcancer.org, 2015)

Retrieved from

<http://www.breastcancer.org/treatment/surgery/reconstruction/types/autologous/lat-dorsi/what-to-expect>



☐ **A** Latissimus dorsi muscle



☐ **A** Latissimus dorsi flap moved to chest area to rebuild breast

